

Planning for Genetic Services in Mississippi

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**Mississippi State Department of Health
Bureau of Child Health
Division of Genetic Services**

In collaboration with

**The Institute for Disability Studies
Mississippi's University Center for Excellence
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Table of Contents

Executive Summary	1
Introduction	3
I. Mississippi State Demographic Profile	5
II. Genetic Services: History and Current Capacity	6
A. History of Genetic Services in Mississippi	7
B. Diagnostic Services.....	8
C. Follow up and Support Services.....	11
D. Utilization of Services	12
E. Financial Resources	20
F. Genetic Education and Training Programs	20
III. Assessing Needs for Genetic Services and their Integration into the Public and Private Service Systems	22
A. Surveying Needs of Consumers, Providers, and Administrators	22
B. Education and Training Needs: Survey of Health Professionals.....	28
C. Comparing Mississippi’s Current Capacity for Genetic Services to ASTHO Standards	29
D. Summary of Assessments and Studies	41
E. Summary of Task Force Discussion on Gaps in Genetic Services.....	43
References	51
Appendices	53
A. The State Health Officer’s Task Force on Genetic Services: Membership List and Meeting Agendas	54
B. Table Appendix B-1: Distribution of Unduplicated Medicaid Recipients <21 Years of Age Receiving Genetic Services by County of Residence and ICD 9 Categories for 2000	59
C. Table Appendix C-1: Distribution of Medicaid Reimbursement Dollars for Genetic Services by County of Recipient Residence and ICD 9 Categories for Children <21, 2000	67
D. Surveys of Professionals and Training Programs/GenESES Genetic Education for the Southeastern States	75
E. A Report of the Consumer, Provider, and Administrator Surveys on Genetic Services in Mississippi	116

List of Tables

Table II-1:	Five-year Trend in Incidence of Congenital Anomalies Among Births and Infant Deaths, Mississippi Residents, 1996-2000	7
Table II-2:	Unduplicated Medicaid Recipients, Providers, and Dollars Reimbursed for Genetic Services to Mississippi Children <21 Years of Age, 2000.....	13
Table II-3:	State Totals of Unduplicated Medicaid Recipients, Dollars Paid and Providers for Genetic Services with Specified ICD-9 Diagnostic Codes for Mississippi Children <21 Years of Age, 2000 ¹	14
Table II-4:	Unduplicated Count of Patients ≤21 Years of Age Served at University of Mississippi Medical Center Division of Medical Genetics by County of Residence, Mississippi, July 1 2000 - June 31, 2001 ¹	18
Table II-5:	Number Served and Dollars Expended in FY 2000 for Children <21 Years of Age with Disabilities and Genetic Disorders, Mississippi	20
Table III-1:	Age of Children of Respondents (Consumer Survey of 2001)	23
Table III-2:	Gender of Children of Respondents (Consumer Survey of 2001).....	23
Table III-3:	Race of Children of Respondents (Consumer Survey of 2001).....	23
Table III-4:	Occupations of Providers Responding (Provider Survey of 2001	25
Table III-5:	Comparison of Issues Ranked Most Important by Consumers, Providers, and Administrators (Consumer, Provider, and Administrator Surveys of 2001)	28

Executive Summary

Genetic disorders are significant causes of morbidity and mortality in Mississippi today and have a tremendous impact on individuals, their families, and society. The rapid growth of knowledge in understanding the role of genetics in inheritance has meant that where once only a few diseases were considered ‘genetic’ now over 4,000 disorders affecting multiple organ systems have been linked to genetic inheritance. This is true for individuals in all age groups. As further research is done and more is known it will be critical for providers to integrate this expanded knowledge into health care services that are accessible, continuous and comprehensive. Anticipating these needs, staff in the Genetic Services Division of the Mississippi State Department of Health (MSDH), undertook a planning process. The State Health Officer appointed a Task Force on Genetic Services to provide oversight for this planning process. The process included a needs assessment—documentation of existing services—and a review of the gaps between these services and the services required. Guidance for integrating required genetic services into state health services was provided from the national Association for State and Territorial Health Officers (ASTHO). The resources needed to fill the gaps were then described in detail and presented for discussion by the Task Force. From these discussions, a final list of Plan priorities was prepared by MSDH staff and submitted to MSDH District Health Officers and central office staff for review and comment. The final draft was then presented to the State Health Officer and State Board of Health for review and amendment; their comments were incorporated into the final Plan. The Plan was then made available on the MSDH Web site and copies are distributed upon request to public and private health providers across the state. **The Genetic Services Plan can be summarized as a framework consisting of five action/issue categories that provide a guideline to future development of initiatives. Certain elements of the Plan have been underway, others will require action in the years to come.**

The final set of action/issue categories that make up the Plan include the following:

Issue #1: Enhanced information system for mother and child population: Data resources exist in various agencies - public and private. What additional data are needed and how do we integrate these for analysis and application? Developing an existing Data Unit at MSDH requires additional dedicated staff to oversee this three-part effort: determination of existing data resources, identification of gaps, specification of new resources that are needed for development of a data integration process and analysis plan.

Support was expressed by the Task Force for an enhanced information system but caution emphasized regarding the many barriers to its achievement. Establishing a super-data unit within the health department/Genetics Division was considered a priority with inclusion of genetic, epidemiologic, biostatistics, and economics expertise. Management of such a unit would require a full-time data manager and an interagency team for guidance and support in integrating information across agencies. Barriers to these accomplishments include the software and hardware incompatibility within and across agencies, and the new Health Insurance Portability and Accountability Act (HIPAA) regulations. A protracted time line was predicted—5-10 years—due to these barriers. A complete initial baseline review was suggested to assess what is available prior to enhancements.

Issue # 2: Integrated and coordinated genetic services must be accessible throughout the state’s public and private health systems. Maintenance of quality and adherence to standards are essential components of these services. A dedicated structure and process is needed to accomplish this goal with sufficient staff for planning, implementation and maintenance of these services.

Support was expressed by the Task Force for integration and coordination of genetic services. Special emphasis was placed on the survival of children with genetic disorders into adulthood; consequently, planning for integration and transition of pediatric services into adult services is the

new challenge for clinicians. The need for national standards for genetic services in clinical practice was stated but none are currently available. Therefore, quality assurance should be under the purview of an advisory group with continuing record reviews—an expensive and labor-intensive process—as an option for quality assurance. It was suggested that the compliance standards used for hospitals could include new standards for genetic services in the lab and the clinic. No support was expressed for law enforcement through punitive measures; rather emphasis should be placed on education and surveillance and reliance on consumer hotlines to monitor compliance.

Issue # 3: Family support services are found across multiple public and private entities; eligibility information about these must be integrated for enhanced consumer and provider access. Such an enhanced information system provides a first step to understanding current options for financial support. Widespread use will identify statewide limitations and suggest opportunities for expansion through legislative and private initiatives. This ambitious work plan requires dedicated staff with expertise and close work with advocacy groups and providers. It was not clear where this work could be implemented.

Unequivocal agreement was voiced by the Task Force that determination of financial eligibility is a time-consuming and cumbersome process that overwhelms consumers, providers, and staff. The use of a web site was supported with consumers entering own eligibility information to receive relevant service options. It was suggested by the Task Force that such a web site would be a joint effort of the Health Department and Department of Human Services. Overcoming transportation barriers through integration of existing programs at Medicaid, Head Start, Early Intervention Services, and Ryan White Programs was discussed. Implementation of this effort would require the initiation of a formal process to involve Medicaid, the departments of Transportation and Education, and Head Start to study availability now. Greater use of satellite clinics was also offered as an option to ease transportation barriers.

Issue #4: Facilitate development of legislative initiatives for genetic services with consumer and provider input and support. Process requires education of and dialogue among consumers, providers, and legislators, and, understanding of current system of genetic services. How should this process be implemented?

This was deemed by the Task Force as the most challenging issue of all. Educating the public and legislature on the importance of genetic services was noted to be very difficult as disease processes are rare. However, it is public awareness and advocacy that drive legislative actions. It was emphasized that vigilance must be exercised in counteracting simplified and false media expressions. Even if a strategic plan were to be employed—a process with an indefinite endpoint—how would we measure its benefits? The establishment of parent support groups should be a joint effort through the Health Department and the March of Dimes using the media to get the public's attention.

Issue # 5: Provider training and education is a critical link to maintenance of standards in genetic testing and patient care. Training provides opportunities for updating with new information and application to consumer services. New information also linked to public and legislator education programs. This work requires dedicated staff and support resources.

While several members voiced support for enhanced professional education, some were skeptical about anyone's ability to impact baccalaureate/professional curricula. Locating this effort within the university system was suggested for pre-service training followed by integrating genetics into continuing education requirements for professional licensure renewals. Continuing education requirements were also cited as a critical focus for presenting new information on genomics to professionals on a regular basis. Caution was expressed that all education on genetics—basic information or new research findings—must be presented with relevance to the practicing professional.

Introduction

Genetics, the study of the biological material that controls inheritance of structures and processes of living organisms, has become the focus of public interest in recent times. Scientists have recognized the potential for this field of study to enhance diagnostic capability and disease therapy, but knowledge and experience in this area are at the earliest stages of development. Media attention has focused on a number of these issues—notably stem cell research and cloning—and debate has begun about the social, ethical, and legal implications of these advances.

The progress made in recent years in understanding the role of genetics in inheritance has meant that where once only a few diseases were considered ‘genetic,’ now over 4,000 disorders affecting multiple organ systems have been linked to genetic inheritance. Three very significant conditions that cause a high proportion of morbidity and mortality in our population—coronary heart disease, cancer, and diabetes—have been associated in part with genetic inheritance. Certain mental retardation conditions have also been linked to genetic inheritance. For every 100 births, between three to five infants will have a significant structural birth defect of which one-fourth will have a genetic link (Genetics Education Center, 2002). The importance of genetics to our society today cannot be ignored.

Nationally,

- 3 to 5 percent of all births result in congenital malformations
- 20 to 30 percent of all infant deaths are due to genetic disorders
- 30 to 50 percent of post neonatal deaths are due to congenital malformations
- 11.1 percent of pediatric hospital admissions are for children with genetic disorders and 18.5 percent are for children with other congenital malformations
- 12 percent of adult hospital admissions are for genetic causes
- 50 percent of mental retardation has a genetic basis
- 15 percent of all cancers have an inherited susceptibility
- 10 percent of the chronic diseases—heart, diabetes, arthritis—occurring in the adult population have a significant genetic component

Source: *Prevalence of Genetic Conditions/Birth Defects: A Variety of References*. Genetics Education Center, University of Kansas Medical Center.

According to the March of Dimes, about 150,000 babies are born with birth defects each year in the United States (4 percent of live births). Using this estimate, of Mississippi’s 44,075 births in

2000, an estimated 1,763 babies were born with birth defects¹. Birth defects are the second leading cause of death among Mississippi's infant deaths: 18 percent, or almost 1 in 5 infant deaths, are the result of birth defects. Of the 468 infant deaths in 2000, 84 were the result of congenital anomalies.

Beyond these grim population statistics are the stories of the individuals affected by genetic disorders and their families. The impact of these disorders on their lives is profound. Family focus necessarily shifts to the care of the disabled child. A child with sickle cell disease, for example, may suffer through multiple and excruciating pain crises, periodic transfusions, and the risk of stroke. There are frequent hospitalizations and visits to the emergency room; there are numerous specialists who must be seen for associated conditions. The child's life is consumed by medical care activities and often normal school attendance falls by the side. Through all of these events, the parent must coordinate medical care, provide emotional support to the child and hold down regular employment.

Beyond the personal human experiences, genetic disorders and birth defects result in enormous financial consequences to individual families and the state as a whole. Few families can bear the financial burden on their own; many, especially in Mississippi, must turn to publicly supported services for care. The magnitude of the public financial burden in Mississippi by the state and the federal government is estimated in this report at \$41,355,997 for FY 2000.

How many individuals are affected by genetic disorders and birth defects? Unfortunately, there is no central repository of data on the number of Mississippians who currently use genetic services and the exact costs. We can safely assume that growth in knowledge of genetics will translate into greater demand for genetic services in the future and so the numbers and costs will rise. We cannot plan for the future growth in genetic services unless we are armed with an understanding of current service utilization and the associated costs.

Mindful of this need, the Mississippi State Department of Health staff in the Division of Genetics made a decision to begin planning for genetic services. An application was submitted to the Health Resources and Services Administration, Genetic Services Branch in the Maternal and Child Health Division for the development of a state genetics plan. An important focus of this proposal was to develop and enhance the use of state information systems and collaborative efforts to support genetic services and integrate them into the health services system. Mississippi's application was successful, and the state joined a number of others receiving federal money for planning genetics services. A few states had already completed the planning process, and their work was reviewed.

The planning process typically involves study of the population in need of service and the services currently offered. These steps are categorized as the assessment phase. There are questions about the population needing services—its size, age distribution, level of education, financial needs, and the kinds of services that are required. Where are the services offered? What are the specific services and the quality of services? How long does it take to get an

¹ For the purpose of this document, individuals who use genetic services include those with genetic disorders and/or birth defects. Genetic disorders are defined as conditions caused by changes in genetic material. A birth defect is an abnormality of structure, function, or metabolism, whether genetically determined or a result of environmental influences during embryonic or fetal life. A birth defect may present from the time of conception through the first year after birth, or later in life.

appointment, is the patient's information there, or does the family have to repeatedly provide information for each provider? How much of a financial burden is on families needing these services? Do patients get information in a way that is understandable? Do families have a clear understanding of the diagnosis and its consequences for their lives? Do families know about the existence of support groups in the state? Does the staff providing services have a good grasp of the diagnosis and the follow up services needed and the existing service system so they can advise families? Once this assessment information is in hand, the gap between services that are available and services required must be evaluated.

This document describes the planning process undertaken by the Mississippi State Department of Health. The first step taken in the process was the appointment of the State Health Officer's Task Force on Genetic Services, a group of stakeholders representing consumers, physicians, lawyers, health services administrators, public agency management, clergy, and third party payors (list of members is shown in Appendix A). The Task Force was convened in August 2001 to introduce the project to the group. Three parents of children with genetic disorders were invited to present their stories to the Task Force to illustrate the challenges that Mississippi families must face on a daily basis. These presentations provided the basis for the Task Force's discussion of the critical issues that had to be included in the Plan. The Task Force was also given a schedule of activities for the planning process. The needs assessment was then implemented by the staff, detailing the state's demographic profile, recording the history and current capacity to provide genetic services, collecting utilization data, and conducting consumer, provider and administrator surveys. The staff also obtained guidelines for integrating genetic services into the health care system from the Association for State and Territorial Health Officers. In addition, staff included a survey done in 1995 by the Institute for Disability Studies at the University of Southern Mississippi to assess the genetic knowledge level and training needs of a variety of health services professionals. The staff then compiled a list of five major issues or categories of activities that were essential to planning future genetic services. On completion of the needs assessment, staff mailed a draft of its findings and convened the Task Force to a second meeting in May 2002. At this meeting, the Task Force reviewed the main issues that would be included in the Plan. The resources and barriers for implementation were discussed and additional considerations were added to each issue.

The plan was presented to the State Health Officer and subsequently to the State Board of Health for review and comment. The final plan then provided the guideline for integrating genetic services into public and private health services.

I. Mississippi State Demographic Profile

Mississippi's total population according to the 2000 Census is 2,844,658 people. The state's population is 61.4 percent white, 36.3 percent African American, 1.4 percent Hispanic, and 0.7 percent Asian. Mississippi's Native American population is 0.4 percent, with most being members of the Choctaw tribe living in east central Mississippi near Philadelphia, headquarters for the Mississippi Band of Choctaw Indians.

Mississippi's population is 48.3 percent male and 51.7 percent female. About one in three Mississippians (27.3 percent) is a child, as there are 775,187 children under age 18 in Mississippi. The state's elderly population accounts for 12.1 percent of the population, with 343,523 people being 65 years of age or older. The state's median age is 33.8. There are

747,159 family households in Mississippi; 363,416 (34.7 percent) have children under the age of 18. Single women head 17 percent of Mississippi's households. The average family size is 3.14 people.

About half (53 percent) of Mississippi's population lives in rural areas. Only seven of the state's 82 counties were included in the Standard Metropolitan Statistical Areas in the 1990 Census. The Census 2000 rural population data has not yet been released, but only slight changes are expected.

In 2000, 19.9 percent of the state's total population lived below the poverty level. In 2000, 16 percent of all families in Mississippi and 40.2 percent of female-headed households lived below the poverty level. Mississippi's median family income was \$37,406 in 1999 (2000 Census). Per capita income for the 2000 Census was \$15,853.

Although Mississippi's economy has been improving in recent years, the state has a long history of poverty. These years of poverty have created a considerable and hard-to-overcome deficit in health, education, and quality of living measures. Mississippi ranked 50th in 1999, the worst in the nation, in teen birth rate (births per 1,000 females ages 15 to 17) according to 2002 KIDS COUNT Data Book. Births to teen mothers are decreasing in Mississippi, but the state's rate of 45 is much higher than the national rate of 29. Mississippi ranked 50th in the percentage of low-birthweight births (less than 5.5 pounds), with 10.3 percent compared to a national average of 7.6 percent.

The Mississippi Department of Education's Office of Special Education reported in their Child Count Report of December 1, 2000, (revised June 22, 2001) that they provided special education services to 59,294 children ages 5 to 21 and to another 6,932 children ages 3 to 5 through the state's public schools. These figures include all disabilities from learning deficits to severe and profound developmental disabilities.

According to the Statistical Abstract of the United States for 2001, in Mississippi in 2000, 80.3 percent of the state's population age 25 years and older had attained high school graduation or more. This number was up from 64.3 percent in 1990. The national average was 84.1 percent in 2000, up from an average of 75.2 percent in 1999. In the year 2000, 17.7 percent of Mississippians 25 years and older were college graduates or had advanced degrees. This same number was 14.7 percent in 1990. The national average in 2000 was 25.6 percent, up from 20.3 percent in 1990.

In December 2000, 18,542 children under the age of 18 with disabilities received \$8,967,000 in Social Security payments. That month, the average monthly payment for recipients was \$483.60. The percentage of children receiving SSI in Mississippi in December 2000—2.4 percent—is double the national average of 1.2 percent and one and a half times the higher Southeastern average of 1.6 percent.

II. Genetic Services: History and Current Capacity

The number of Mississippi births, which rose to a high of 66,128 in 1949, dropped from the 50,000s to the 40,000s in 1966. Throughout the 1990s, the total number of births in Mississippi has remained in the lower 40,000s. In 2000, the latest reporting year, 44,075 babies were born.

Of these babies, 489 were reported with congenital anomalies on their birth certificates, and 84 babies died from anomalies.

Table II-1: Five-year Trend in Incidence of Congenital Anomalies Among Births and Infant Deaths, Mississippi Residents, 1996-2000¹

Year of Birth or Infant Death ²	Congenital Anomalies Reported Among Live Births			Congenital Anomalies Reported as Cause of Death		
	Number	Total Live Births	Percent of Total Live Births	Number	Total Infant Deaths	Percent of Total Infant Deaths
1996	541	40,978	1.32	102	451	22.6
1997	554	41,527	1.33	92	440	20.9
1998	577	42,917	1.34	79	436	18.1
1999	454	42,678	1.06	68	435	15.6
2000	489	44,075	1.11	84	468	17.9
Five Year Total	2,615	212,175	1.23	425	2,230	19.1

1. Source: Mississippi State Department of Health, Vital Records

2. Data are presented for year of occurrence, so infant deaths are those reported for the year indicated and are not of infants born in the year indicated.

These figures are only a part of the total number of children born with genetic disorders since many disorders are diagnosed as the babies grow and develop. According to the National Early Intervention Longitudinal Study published by SRI International in September 2001, 38 percent of children begin early intervention programs between birth and 12 months of age, with one in five entering early intervention in their first 6 months of life. Another 28 percent of children enter early intervention in their second year. More than one-third of the children entered early intervention services after their second birthday. Of the children in the survey, 8.9 percent had congenital disorders, with 4.3 percent of those children having Down syndrome. The report also showed that children with congenital disorders were the youngest group at entry to early intervention—at 7.9 months on average—because these conditions are usually identified at birth.

A. History of Genetic Services in Mississippi

Dr. John Jackson has often been deemed the father of genetics in Mississippi. Dr. Jackson and his small staff began their work at the University of Mississippi Medical Center in Jackson in the mid-1960s when researchers prepared chromosomes for testing by smashing samples onto cards with their thumbs. Genetic testing was not routine.

Advanced research and improved medical technologies have created increased interest and concern in genetic testing. Early screening allowed for preventive measures that could minimize recurrence. By the early 1980s, newborns at larger Mississippi hospitals were tested by a heel-prick drawn blood sample for phenylketonuria (PKU). Other genetic tests were added, but testing was not mandatory and was not performed uniformly across the state.

Legislative action was pursued. Sections 41-21-201 and 41-21-203 of the Mississippi Code of 1972, Annotated, authorized the Department of Health to adopt rules and regulations to provide mandatory statewide testing for PKU and hypothyroidism through the Newborn Screening and Follow-up Program. During this time, a link was formed between the Health Department's Genetic Screening program and the Medical Genetics program at the University of Mississippi Medical Center that made confirmatory and follow-up services possible for the babies and their families identified through newborn screening.

Several years later, Sections 41-24-1 through 41-24-5 of the Mississippi Code of 1972, Annotated, authorized the Department of Health to provide for additional testing for galactosemia and hemoglobinopathies, such as sickle cell trait and sickle cell anemia as well as to educate the public on these disorders. This statute provides for the screening of PKU, hypothyroidism, galactosemia, and hemoglobinopathies to be conducted statewide. Under this statute, the physician attending a newborn is held responsible for ensuring that the baby receives these tests. State law exempts newborns from testing if the parents object on the grounds that such tests conflict with their religious practices or tenets.

The Birth Defects Registry became law in July 1997 with the passage of Section 41-21-205 of the Mississippi Code. This law authorized the Department of Health to establish the operation of a registry program to identify and investigate birth defects and to maintain a central registry of cases of birth defects identified from birth to age 21. Data collection for the birth defects registry began January 1, 2000.

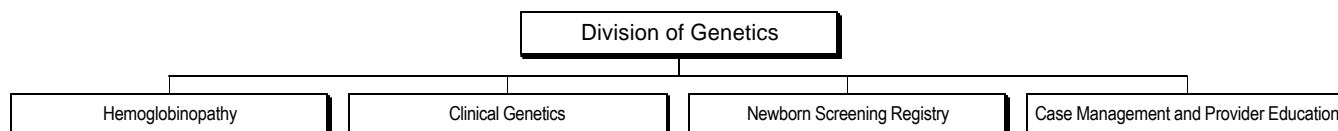
During the 2001 legislative session, Section 41-21-203, Mississippi Code of 1972 was amended to authorize the Department of Health to include testing for congenital adrenal hyperplasia as part of the newborn screening program. This additional testing began on March 1, 2002. This amendment also requires the physician or person attending a birth to notify the parents of a newborn that there are other optional screening tests for approximately 30 disorders available, in addition to the five required tests, for a fee.

B. Diagnostic Services

The Genetics program of the State Department of Health was created in October 1982 to provide screening, diagnosis, counseling, and follow-up for a range of genetic disorders mandated by legislation. Through the years, the program has expanded and developed comprehensive genetic services statewide. The program became the Division of Genetics on July 1, 1999. The Genetics Division provides newborn screening to identify these problems early and allows for immediate intervention to prevent irreversible physical and developmental disabilities or death where clinically possible. The Division also tests patients for maternal serum alpha-fetoprotein.

The Division of Genetics has four branches: Hemoglobinopathies, Clinical Genetics, Screening Surveillance, and Case Management and Provider Education.

Organizational Chart



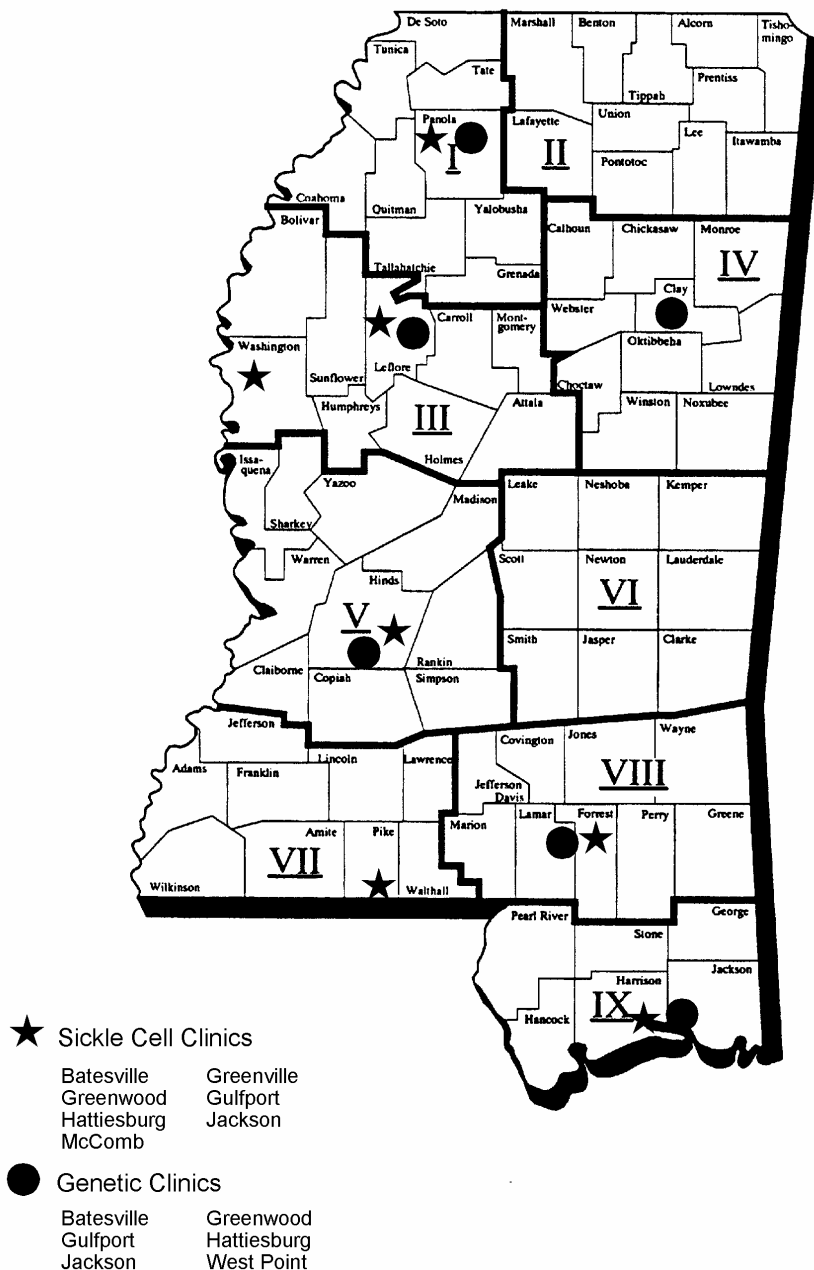
Hemoglobinopathy Services provides quality screening, education, treatment, and follow-up for sickle cell disease patients. The purpose of this branch is to reduce mortality and morbidity resulting from sickle cell disease and other hemoglobinopathies. Because Mississippi is a rural state, services are provided in Jackson at the University of Mississippi Medical Center and at six satellite clinics located across the state—Batesville, Greenville, Greenwood, Gulfport, Hattiesburg, and McComb. These clinics are convenient and less costly to the parents of children with sickle cell disease. A physician, a nurse, and a social worker staff each clinic. These clinics also allow the opportunity for clinic physicians and local physicians to interact and form patient-

centered working relationships, with clinic physicians having the opportunity to educate local physicians on current sickle cell treatment.

Clinical Genetics provides comprehensive genetic services statewide. These services include clinical screening, counseling, and short- and long-term follow-up of a broad range of genetic related disorders. Genetic clinics are located in Jackson at Blake Clinic for Children, the primary clinic of the state's Children's Medical Program, with clinics in five additional areas of the state—Batesville, Greenwood, Gulfport, Hattiesburg, and West Point. Georg Bock, M.D., Ph.D., F.A.C.M.G., director of the Division of Medical Genetics and his personnel at the University of Mississippi Medical Center, staff most of these clinics. There is one private physician providing genetic services in north Mississippi. Each year over 1,000 patients are seen in genetic satellite clinics statewide.

In an average year, it is expected that four PKU cases, 12 hypothyroid cases, one galactosemia case, and at least 60 hemoglobinopathy cases will be identified through the screening of Mississippi newborns. About 5 percent of the state's newborns, approximately 2,200 babies, have to be retested because of poorly collected specimens or early discharge.

Health Department Genetic and Sickle Cell Clinics



The goal of the **Newborn Screening Registry** is early detection and prevention. Programs are instituted to identify at risk infants in the first few days of life so that early intervention can be implemented. Newborns are tested at the state's more than 55 hospitals in the state that deliver babies.

The Department of Health Genetics Division has had a mandate for a birth defects surveillance system in Mississippi since July 1997. The Division is using this system for birth defects surveillance to identify infants and children with birth defects so the children can be followed by the First Steps Early Intervention Program, the Children's Medical Program, the Perinatal High Risk Management (PHRM) program, and other appropriate programs.

The **Case Management and Provider Education** branch provides education to over 55 hospital nurseries and laboratories and over 101 Health Department clinics concerning newborn screening and the importance of prophylactic antibiotics in the treatment of children with significant hemoglobinopathies. The Division of Genetics continues to hold meetings across the state with emergency room physicians, pediatricians, and public health physicians on the most current protocols for care and treatment of sickle cell patients, emergency treatment, and pain crisis. Literature is researched and mailed during the year to sickle cell disease patients' physicians, and sickle cell identification cards are provided to all Mississippi patients.

The Division of Genetics uses the Mississippi State Department of Health's infrastructure of clinics, case management, screening, testing, follow-up, and treatments in the state's nine public health regions to assist in providing the best services for patients with genetic needs.

C. Follow up and Support Services:

First Steps, Mississippi's Early Intervention Program (EIP), provides intervention services to infants and toddlers through age two who are experiencing developmental delays or have a diagnosed physical or mental condition that has a high probability of resulting in developmental delay. Eligible children receive assessment and evaluation, and Individual Family Services Plans (IFSP) are created. The IFSP details the services recommended and the coordination of those services. In FY 2000, the Early Intervention Program served 1,245 children.

The **Children's Medical Program (CMP)** provides medical and surgical care to Mississippi children with disabilities and chronic illness up to age 21. Conditions covered include major orthopedic, neurological, cardiac, and other chronic conditions such as cystic fibrosis, sickle cell anemia, and hemophilia. The Children's Medical Program operates a central multi-discipline clinic at Blake Clinic for Children in Jackson in addition to operating more than 650 clinic sessions a year at 19 separate sites around the state. There is a CMP coordinator in each of the state's nine health districts.

The **Perinatal High Risk Management (PHRM) Infant Services System** focuses on lowering the infant and maternal mortality and morbidity rates in Mississippi. PHRM provides comprehensive, individualized, enhanced services, including medical, nursing, nutrition and social services, to high-risk pregnant women and infants as early as possible. This program served 22,408 high-risk mothers and infants in FY 2002.

D. Utilization of Services

A number of agencies and third party payors were contacted to obtain statistics on current utilization of services by individuals with genetic disorders. Requests were submitted to the Division of Medicaid, Blue Cross Blue Shield of Mississippi, University of Mississippi Medical Center Division of Genetics, and internally at the Department of Health, Division of Genetic Services, Early Intervention/First Steps Program, Perinatal High Risk Program, and Children's Medical Program. Data that were available from the Division of Medicaid and the University of Mississippi Medical Center are presented on Table II - 2 through II - 5 in this section. Blue Cross Blue Shield of Mississippi was unable to provide data on utilization of genetic services.

1. Division of Medicaid data shown on Tables II-2 show the total count of unduplicated recipients <21 years of age, the total number of unduplicated providers billing, and the total dollars spent for those recipients with a primary diagnosis found on the ICD-9 list of genetic disorders/anomalies. The data cover Fiscal Year 2000. The table shows a total of \$18,364,234 was spent by the Division of Medicaid for 18,116 unduplicated recipients receiving genetic and related services from 4,482 providers in the state in FY 2000. The disorder with the highest number of unduplicated recipients is congenital anomalies at 8,098. Additional disorders that cost the state over 1 million dollars also include anemias, endocrine disorders and nervous system disorders. Congenital anomalies were the costliest per recipient among all the disorders - the Medicaid Program spent an average of \$1,336 per recipient. Next on the list were the anemias at \$1,227 per recipient and nervous system disorders at \$1,015 per recipient.

Table II-3 shows the same data aggregated for all diagnoses and distributed by the individual counties. This table was constructed to attempt a comparison of utilization of Medicaid across the counties. The count of unduplicated recipients coincides with the overall county population, with Hinds and Harrison counties each showing about double the number of recipients as found in the three other counties with the next highest numbers of recipients - Washington, Forrest and Jackson. In an effort to standardize the county comparison, the recipient count was calculated as a percentage of all Medicaid eligible children in each county since it accounts for the level of Medicaid eligibility among the child population of the county. Overall, 5.4 percent of the state's Medicaid eligible children less than 21 years of age received genetic services with the counties ranging between a low of 3.3 percent in Tunica County to a high of 15.7 percent in Walthall County.

The unduplicated provider count is presented on Table II-3 because it demonstrates the availability of providers to the population in need of services in each of the counties. Note that these providers may or may not be located in the particular county listed - these are the providers accessed by the patients.

County by county distributions of recipients and dollars spent are shown for each ICD-9 diagnostic category in the Appendices B and C.

Table II-2: State Totals of Unduplicated Medicaid Recipients, Dollars Paid, and Providers for Genetic Services with Specified ICD-9 Diagnostic Codes for Mississippi Children <21 years of age, 2000¹

ICD 9 Diagnosis Description and Code	Unduplicated Recipients	Dollars Paid to Providers	Unduplicated Providers Serving Recipients
Wilm's tumor, retinoblastoma, other congenital neoplasms (189-191)	65	100,388	54
Endocrine disorders (237-259)	2,830	1,384,517	961
Metabolic and immune disorders (270-275)	665	153,647	262
Metabolic and immune disorders (277-279)	1,369	669,306	434
Specified anemias, coagulation defects (282-284)	2,742	3,365,628	640
Specified anemias, coagulation defects (286)	1	13	1
Nervous system disorders (330-343)	1,041	1,057,462	392
Nervous system disorders (352-359)	245	137,637	183
Retinal disorders (362-363)	860	216,378	140
Blindness (369)	1	164	1
Hearing loss (389)	14	971	10
Cardiomyopathy and conduction disorders (Exclude 427.5 cardiac arrest) (425-427)	183	452,571	107
Dentofacial anomalies (524)	2	549	2
Congenital anomalies (740-759)	8,098	10,825,003	1,295
State Totals	18,116	\$18,364,234	4,482

Source: Division of Medicaid, Mississippi.

Table II-3: Unduplicated Medicaid Recipients, Providers and Dollars Reimbursed for Genetic Services to Mississippi Children <21 Years of Age, 2000¹

County	Unduplicated Recipient Count	Recipients ² as Percent of Eligibles <21	Unduplicated Provider ³ Count	Total Dollars Reimbursed to Providers
Adams	321	6.4	26	255,622
Alcorn	176	5.6	23	85,590
Amite	98	5.9	2	108,761
Attala	163	6.5	6	195,308
Benton	70	6.7	4	16,455
Bolivar	375	4.3	15	391,036
Calhoun	85	5.0	9	66,721
Carroll	51	4.7	2	33,632
Chickasaw	120	5.8	14	113,821
Choctaw	86	6.6	3	74,157
Claiborne	94	4.7	5	91,749
Clarke	96	6.0	8	103,924
Clay	168	5.4	7	87,114
Coahoma	278	3.8	23	389,628
Copiah	237	5.7	8	207,374
Covington	155	5.8	10	196,206
DeSoto	234	5.1	14	134,156
Forrest	561	6.3	68	567,137
Franklin	82	6.3	6	47,899
George	98	4.6	8	84,692
Greene	60	4.6	2	90,044
Grenada	129	4.5	18	366,993
Hancock	208	5.4	12	135,315
Harrison	1,177	6.8	84	1,374,380
Hinds	1,721	5.5	120	2,249,674
Holmes	320	5.6	13	164,382
Humphreys	146	5.3	9	82,707
Issaquena	14	4.1	-	2,905

Notes: 1. Source: Data provided by the Division of Medicaid. 2. Recipients of genetic services as percent of all eligibles <21. 3. "Unduplicated provider count" is the count generated by the unique billing numbers that are submitted by individual providers, individual hospital departments and clinics with multiple professionals on staff. This count does not represent only individual providers.

Table II-3 (Continued): Unduplicated Medicaid Recipients, Providers and Dollars Reimbursed for Genetic Services to Mississippi Children <21 Years of Age, 2000¹

County	Unduplicated Recipient Count	Recipients ² as Percent of Eligibles <21	Unduplicated Provider ³ Count	Total Dollars Reimbursed to Providers
Itawamba	75	4.5	6	47,582
Jackson	547	4.9	39	427,303
Jasper	116	5.1	8	77,223
Jefferson	82	4.7	5	43,001
Jefferson Davis	135	5.7	6	104,784
Jones	465	6.3	25	480,518
Kemper	64	5.5	-	51,506
Lafayette	110	5.1	22	385,453
Lamar	219	6.5	15	153,640
Lauderdale	396	4.6	53	389,839
Lawrence	92	5.8	8	74,160
Leake	150	5.9	9	187,003
Lee	320	4.8	43	335,093
Leflore	388	4.9	22	285,966
Lincoln	188	4.9	10	99,617
Lowndes	418	5.6	29	445,045
Madison	413	6.0	18	330,930
Marion	295	7.6	16	240,710
Marshall	152	4.0	8	168,453
Monroe	154	3.9	24	176,577
Montgomery	68	4.1	10	72,204
Neshoba	198	5.7	12	171,417
Newton	117	5.1	18	128,328
Noxubee	119	4.6	9	269,077
Oktibbeha	214	5.6	14	168,913
Panola	249	4.6	19	295,416
Pearl River	283	5.4	17	273,942

Notes: 1. Source: Data provided by the Division of Medicaid. 2. Recipients of genetic services as percent of all eligibles <21 3. "Unduplicated provider count" is the count generated by the unique billing numbers that are submitted by individual providers, individual hospital departments and clinics with multiple professionals on staff. This count does not represent only individual providers

Table II-3 (Continued): Unduplicated Medicaid Recipients, Providers and Dollars Reimbursed for Genetic Services to Mississippi Children <21 Years of Age, 2000¹

County	Unduplicated Recipient Count	Recipients ² as Percent of Eligibles <21	Unduplicated Provider ³ Count	Total Dollars Reimbursed to Providers
Perry	107	6.4	6	51,525
Pike	341	5.5	24	241,490
Pontotoc	82	4.2	5	68,814
Prentiss	104	4.8	10	392,492
Quitman	127	5.7	9	101,802
Rankin	388	5.7	20	417,814
Scott	230	6.4	14	142,885
Sharkey	83	4.8	8	34,251
Simpson	205	6.2	18	238,472
Smith	118	6.4	2	88,057
Stone	125	7.4	9	188,653
Sunflower	263	3.5	14	233,476
Tallahatchie	146	5.5	7	111,665
Tate	117	5.0	6	154,048
Tippah	100	5.0	12	149,935
Tishomingo	80	5.3	7	171,336
Tunica	60	3.3	4	85,089
Union	86	4.4	8	57,782
Walthall	388	15.7	9	125,919
Warren	333	5.1	16	282,765
Washington	662	4.8	38	723,115
Wayne	131	4.6	12	104,029
Webster	54	4.9	5	56,478
Wilkinson	90	5.0	14	62,758
Winston	130	4.9	8	97,687
Yalobusha	61	3.5	7	76,138
Yazoo	243	4.5	12	239,367
Total State	18,116	5.4	1,288	18,294,924

Notes: 1. Source: Data provided by the Division of Medicaid. 2. Recipients of genetic services as percent of all eligibles <21. 3. "Unduplicated provider count" is the count generated by the unique billing numbers that are submitted by individual providers, individual hospital departments and clinics with multiple professionals on staff. This count does not represent only individual providers.

2. University of Mississippi Medical Center/Division of Medical Genetics provided data on the numbers of children ≤ 21 years of age served in University of Mississippi Medical Center Genetics Clinic for the Fiscal Year July 1, 2000 - June 31, 2001 (Table II-5 on page 22). A total of 596 individuals ≤ 21 years of age received services at the University of Mississippi Medical Genetics Clinic in this time period. Hinds County had the highest representation in this group with 66 residents, followed by Madison County with 32, and Rankin County with 31.

Table II-4: Unduplicated Count of Patients ≤ 21 Years of Age Served at University of Mississippi Medical Center Division of Medical Genetics by County of Residence, Mississippi, July 1, 2000 - June 31, 2001¹

County	Patient Count	County	Patient Count	County	Patient Count
Adams	7	Itawamba	2	Pike	10
Alcorn	0	Jackson	7	Pontotoc	1
Amite	3	Jasper	7	Prentiss	0
Attala	4	Jefferson	2	Quitman	0
Benton	0	Jeff Davis	2	Rankin	31
Bolivar	8	Jones	18	Scott	8
Calhoun	0	Kemper	0	Sharkey	1
Carroll	3	Lafayette	0	Simpson	7
Chickasaw	4	Lamar	4	Smith	6
Choctaw	3	Lauderdale	23	Stone	3
Claiborne	4	Lawrence	6	Sunflower	13
Clarke	9	Leake	6	Tallahatchie	0
Clay	4	Lee	4	Tate	1
Coahoma	0	Leflore	21	Tippah	1
Copiah	11	Lincoln	10	Tishomingo	1
Covington	11	Lowndes	16	Tunica	0
DeSoto	1	Madison	32	Union	0
Forrest	11	Marion	6	Walthall	3
Franklin	5	Marshall	5	Warren	10
George	5	Monroe	12	Washington	11
Greene	1	Montgomery	5	Wayne	4
Grenada	2	Neshoba	13	Webster	3
Hancock	9	Newton	5	Wilkinson	1
Harrison	15	Noxubee	4	Winston	7
Hinds	66	Oktibbeha	2	Yalobusha	1
Holmes	6	Panola	4	Yazoo	13
Humphreys	3	Pearl River	7	Unknown	37
Issaquena	1	Perry	4	Total State	596

Notes: 1. Source: Data provided by the University of Mississippi Division of Medical Genetics.

4. Mississippi State Department of Health has a number of programs and divisions that serve the child population with genetic disorders/anomalies. Data available for each are shown as follows:

- a. **Division of Genetic Services** provided data on screening for FY 2000 for each of the state's 44,075 live births. In this cohort were found the following:

Screening Test	Positive Screens	Confirmed Cases	Cases Receiving Treatment
Phenylketonuria	29	1	1
Congenital hypothyroidism	30	2	2
Galactosemia	34	0	0
Sickle Cell Disease	114	56	56

Further:

- Of the state's 44,075 live births, 41,611 were screened for hearing impairment before hospital discharge.
- Of the 419 infants screened and referred for hearing impairment greater than or equal to 35 dB nHL, all received follow-up and intervention upon hospital discharge.
- Of the state's 44,075 live births 121 were born with neural tube defects.
- The Division's six Genetics Clinics and seven Sickle Cell Clinics served more than 1,500 patients in FY 2000.

- b. **Children's Medical Program**, (the state's Children with Special Health Care Needs Program), served a total of 3,988 children in FY 2000 either through direct services or through payment for referral services. A total of \$3.8 million was spent on diagnostic and treatment services for children with special health care needs. Services included hospitalization, physician's services, appliances, artificial limbs, and medications. Funding for this program comes primarily from the Title V MCH Block Grant with the State of Mississippi contributing other funds.

- c. **First Steps Early Intervention System (FSEIS)** served a total of 3,136 children during FY 2000.

- d. **Perinatal High Risk Program (PHRM)** served 18,343 high-risk mothers and infants in FY 2000.

5. Social Security Benefits for Children with Disabilities (SSI) served 18,542 children <18 years of age in FY 2000.

Summary of information on utilization statistics

It is apparent that there is a lack of coordination and integration of data on children receiving genetic services across the multiple agencies providing services or reimbursement. Even within the Department of Health there is no centralized record keeping on children with genetic disorders in the multiple programs that are offered there. The lack of a uniform and integrated

data base frustrates providers who must work with other providers within or outside their own institutions, administrators who must review the care process and its outcomes, and planners who have no data for determining existing system operations and needs for future enhancement. Most importantly, such a state of disorganization impacts the child with genetic disease and his/her family as they negotiate a complex web of services, and seek financial assistance and answers to questions about the care process.

E. Financial Resources

A search for data on financial resources and expenditures by families with children with genetic disorders also demonstrated a variety of data from individual agencies/entities - there was no single source of information. Data was therefore collected from the various state agencies and private insurers who provided services, reimbursed for services, or provided monthly benefits for children. Dollars spent for program administration were also included. According to data released by The Children's Defense Fund, in the 1999 Mississippi Profile, 18.2 percent of all children in Mississippi were uninsured - a total estimated at 152,000. An analysis conducted by the Children's Medical Program in FY 1999, revealed that 86.5 percent of its patients were covered by Medicaid, 2.7 percent were covered by private commercial insurance, and 10.8 percent had no source of insurance for primary and specialty care.

Table II-5: Number Served and Dollars Expended in FY 2000 for Children <21 Years of Age with Disabilities and Genetic Disorders, Mississippi.

Program/ Agency Name	Number of Children Served in FY 2000	Dollars Spent for Children in FY 2000
Division of Genetics (MSDH)	5,105	\$ 1,363,706
Children's Medical Program (MSDH)	3,988	\$ 3,528,554
PHRM (MSDH)	4,932	\$ 3,104,465
Early Intervention (MSDH)	3,136	\$ 5,627,859
Division of Medicaid	18,116	\$18,364,234
SSI Benefits/Disability Determination (Social Security)	18,542	\$ 8,967,000
Totals	53,819	\$41,355,997

F. Genetic Education and Training Programs

There are a number of genetic education and training programs in place in Mississippi. These include genetic training as part of curricula for professional degree programs; others are available at the postgraduate level.

1. Baccalaureate/Pre-Service Training. There are 19 training programs in Mississippi that prepare a variety of professionals for health care services (including nurses, social workers, psychologists, speech language pathologists and special education teachers). A survey was done in 1995 targeting these training programs in a variety of institutions of higher learning in Mississippi to determine the breadth and depth of genetic training in pre-service education. The findings of this telephone survey of training programs confirm reports in the national literature

that genetic education is limited in these programs and verify the findings of the survey of professionals (see Section III, B). Even though a majority of programs (79 percent) teach the clinical aspects of genetic disorders, few include information about the Human Genome Project (HGP). Among programs that do describe the HGP there is a very limited coverage of the ethical, legal and social implications of the new genetics. Teaching about recent molecular advances and their implications in genetic disorders was reported by very few of the programs surveyed. These results demonstrated the need to expand genetic education in professional training programs to enhance awareness of the critical role played by genetics in the practice of professionals and to build a knowledge base that supports that practice.

2. Post-Graduate Educational Opportunities expanded in this state in 1984 when the Institute for Disability Studies at the University of Southern Mississippi (IDS/USM), the Genetics Program of the Mississippi State Department of Health (MSDH) and the Division of Medical Genetics at the University of Mississippi Medical Center (UMC) joined informally to offer workshops titled Interdisciplinary Approach to Genetic Case Studies: Focus on Families. Support for these seminars was provided through the Maternal and Child Health Project, Health Resources and Services Administration, and the Administration on Developmental Disabilities Department of Health and Human Services. The purpose of this continuing series of seminars was to add to and enhance skills of practicing professionals in the fields of health, education, social work and psychology in working with families with genetic disorders using a collaborative, interdisciplinary model. Seminar sessions discussed similarities and differences in professional roles within the fields of health, education, social work and psychology. Issues and trends in the field of genetics were examined using the case study approach. Additionally, parent/professional collaborative approaches to service delivery for children with genetic problems were shared with seminar participants. Participating families voiced their concerns and their desires to have practitioners become more sensitive to family input and to change their service delivery patterns.

In 1995 these seminars were presented in three different locations in Mississippi with a total of 235 professionals and families participating from different areas of the state. The participants represented families and professionals from education, nutrition, nursing, speech and hearing, psychology, social work and medicine. A total of 11 families were involved in training the participating professionals with 34 cross-discipline professional presenters relating information pertinent to each case study. Satisfaction with didactic instruction and overall satisfaction with the seminars were evident from high ratings given by seminar participants on post seminar evaluations. Professional participants indicated they were more conscious of consumer needs as a result of information shared through the seminars.

In reviewing the impact of the Human Genome Project on the future knowledge base and clinical practice requirements of health, education and human services providers, the IDS/USM, MSDH, and UMC recognized the urgent need to expand the existing education seminar series. A formal framework, the GenESES (Genetic Education for Southeastern States) Consortium, and process were deemed essential to the development and implementation of expanded GenESES goals. The GenESES Mississippi Advisory Council was established and convened in August 1994, to plan a project that would develop a curriculum for training health, education, and human service professionals in the south.

Project funding came through a grant from the National Institutes of Health/Human Genome Project/Ethical, Legal, and Social Implications Branch. Early on, the IDS, MSDH, and UMC project staff recognized that courses at the pre-service level had not incorporated content about

genetics and the inherent ethical, legal, and social issues. It was anticipated that the curriculum under development would also be useful to faculty in fields such as nursing, social work, and special education. To test the curriculum with students, 13 lectures ranging from 3-6 hours (often broken into multiple class sessions) were delivered. Through these lectures 405 undergraduate and graduate students received training in genetics and represented the academic majors of child development (127), community health science (30), education (4), nutrition (1), psychology (61), special education (120), speech language pathology (13), social work (20), and therapeutic recreation (24). Modifications in the curriculum were made to reflect instructor and student feedback.

Once the curriculum had been field-tested and revised, it was ready for review by regional reviewers. These reviewers were compensated by the project to edit and respond to the curriculum. Reviewers included Mary Z. Pelias, Ph.D., J.D., FFACMG, Professor of Genetics from Louisiana State University Medical Center; Vicky Pratt, Ph. D., FACMG, Associate Director of Molecular Biology from Research Triangle Park, North Carolina; Mary Ann Henson, R.N., M.S.N., Genetics Program Manager from the Georgia Department of Human Resources; Kristin Paulyson, M.S., Genetic Counselor from Duke University Medical Center; and Vickie Hannig, M.S., C.G.C., Genetic Counselor from Vanderbilt University Medical Center. The completed curriculum was presented by project staff at a SERGG meeting in Atlanta and at the Southern Genetics Group meeting. Copies of the completed 250-page curriculum were sent to 50 key members of SERGG, as well as targeted southeastern schools of nursing, social work, community health, nutrition, and special education.

III. Assessing Needs for Genetic Services and Their Integration into Public and Private Service Systems

In this chapter genetic services will be evaluated to determine how well they comply with:

- Consumer, provider, and program administrator needs
- National standards set by the Association of State and Territorial Health Officers (ASTHO)

Furthermore, the results of a survey of education and training needs of professionals will be presented to add detail to this important need identified by providers.

A. Surveying needs of consumers, providers and program administrators

Three surveys were developed for the Genetics Services Planning Project of the Genetics Division of the Mississippi State Department of Health to determine perceptions regarding genetic services as expressed by consumers, providers, and administrators. A full report on these surveys is included in Appendix E.

1. Consumer Survey

A total of 625 surveys were mailed to parents of children with disabilities and 116 were returned—an 18.6 percent rate of return. The children of these respondents were distributed as follows for age, sex, and race:

Table III -1: Age of Children of Respondents

Age Group	Percent
0-3 years of age	36%
4-12 years of age	28%
13-21 years of age	14%
>21 years of age	13%
No Response	9%
Total	100%

Table III - 2: Gender of Children of Respondents

Gender	Percent
Male	58%
Female	36%
No Response	6%
Total	100%

Table III - 3: Race of Children of Respondents

Race	Percent
White	44%
Non White	50%
No Response	6%
Total	100%

There were 14 possible problems listed on the survey that may be of significance to parents in caring for their children. These were ranked by respondents in order of importance with the following three ranking the highest:

22 percent noted it was *Not clear what financial coverage is available to us,*

19.3 percent noted *There are no specialized doctors close by so we have to travel far for some appointments,* and

15.6 percent noted they *Can't find child care for my child with disabilities.*

Three other problem issues ranking highly with over 10 percent of respondents include the following:

We have not received information on parent support groups near where we live by 12.8 percent,

We have problems getting transportation for our children's appointments by 11 percent, and

Because of transportation problems I sometimes have a hard time keeping appointments by 10.1 percent.

(Note that parents listed several issues with a “1” for the most critical or a “2” as the next most critical, etc., hence these percentages do not total 100 percent).

It can be summarized then that the following issues are important to parents of children who require genetic services:

1. Understanding availability of financial coverage
2. Local availability of specialized physicians
3. Child care
4. Access to parent support groups
5. Transportation

The results also showed that of the above listed issues, transportation and access to information were more frequently mentioned as problems—over 50 percent more frequently—for black parents. Differences in perceptions by race regarding transportation and access to information are not surprising given the disparity in socioeconomic status between whites and blacks in Mississippi. Because respondents were not asked questions regarding socioeconomic status their answers cannot be definitively linked to this variable.

Geographic location also differentiated parents: those living in the southern portion of the state cited transportation and understanding financial coverage 50 percent more frequently as problem issues than parents living in the central and northern regions of the state. These differences are explained by the greater accessibility in central Mississippi to the state’s tertiary care center at the University of Mississippi Medical Center. In the northern portion of the state access to tertiary care is found in Memphis, Tennessee, at LeBonheur Children’s Medical Center and in Tupelo, Mississippi, at the North Mississippi Medical Center. Access to tertiary care in the southern portion of the state is more limited.

Positive consumer opinions included the following:

Genetics services have been a big help. When we call them they respond quickly.

Genetic screening of our child alleviated some of the concern that her condition was hereditary. Although her condition is genetic, it is a random occurrence condition.

At birth, genetic services were very helpful in explaining our diagnosis of Down syndrome.

2. Provider Survey

A total of 855 surveys were mailed to seven groups of providers working in the Mississippi State Department of Health, University Medical Center, and community health centers around the state. Other providers included members of the Mississippi Perinatal Association and the Mississippi Chapter of the American Academy of Pediatrics. A total of 208 surveys were returned—a 24 percent return rate, by providers in 71 of 82 counties. All providers responded that they saw patients with birth defects and genetic disorders. These providers were distributed as follows by type of occupation:

Table III - 4: Occupations of Providers Responding

Occupation	Percent Among Respondents
Physicians	52%
Nurses	30%
Early Intervention Specialists	8%
Nurse Practitioners	3%
Social Workers	3%
Other	4%
Total	100%

Of 16 issues listed as important in caring for patients with genetic diagnoses, the following ranked in the top three by providers:

Not having specialized doctors available to refer patients close to their homes by 27.4 percent,

Overall management of patient is not coordinated among providers so there are duplications/gaps by 20.2 percent, and

Limited availability of training programs to keep my skills up to date by 14.4 percent.

An additional six issues were rated as important by over 10 percent of respondents:

Other providers are not aware of nor do they understand what services we can provide (13.9 percent),

Appointment keeping is a problem (13 percent),

Do not have a list of support groups available for referral of parents in our area (12.5 percent),

Not enough skilled professionals (12.5 percent),

No transportation for our patients to get here (12.5 percent), and

Incomplete information available on patients referred to me by other providers (11.1 percent).

(Note that providers ranked several issues with a “1” for the most critical or a “2” as the next most critical, etc., hence these percentages do not total 100 percent.)

It can be summarized then, that responding providers of genetic services have the following major issues in caring for children with genetic conditions and disabilities:

1. Insufficient skilled professionals for referrals
2. Uncoordinated care management and information regarding patient care
3. Lack of training programs to maintain skills
4. Lack of information for providers regarding service availability and parent support groups
5. Transportation for patients

Differences in responses were observed among physicians, nurses and other provider types. Nurses chose 12 issues more frequently—some 50 percent more frequently—than physicians and other providers as their most important problem: patient transportation, duplication in patient management, incomplete patient information, no specialized doctors close to patient's home, too many forms, lack of affordable child care, difficult system of care, limited training available, problem keeping appointments, other providers not aware of services, long wait for follow-up appointments, and no list of local support groups. This finding is not unexpected given the typical role of the nurse in managing and coordinating patient care and the greater ease of patients in communicating with nurses rather than doctors. Nurses are therefore more aware of patient service problems than doctors.

Differences in responses were also noted by geographic location of the provider. Service coordination and availability of specialized doctors were two issues mentioned most frequently as problems for the southern portion of the state. As noted earlier these observations are related to the lack of accessible tertiary care specialists in southern Mississippi and the presence of a tertiary medical center in central Mississippi and limited referral access in northern Mississippi in Tupelo and in Memphis, Tennessee.

Open ended comments included general complaints about the lack of resources, lack of education, and need for follow-up information on newborn genetic screening for primary care providers. Other providers indicated their search for and implementation of priorities and programs that can work for people with genetic disorders and their families.

Specific mention was made of transportation assistance, coordination of services, resources for referrals, and education and training.

3. Administrator Survey

A total of 89 surveys were mailed to program administrators in the Mississippi State Department of Health, University Medical Center, community health centers around the state, and the Division of Medicaid. Of these, 41 were returned—a 46 percent rate of return. Administrators from programs in 36 counties and 5 different Health Department districts responded.

Of the 16 issues listed by administrators as important in caring for patients with genetic diagnoses, the top three included:

Transportation to our location is a problem for our patients by 47.5 percent,

Don't have available enough skilled professionals to staff program by 30 percent, and

Not having specialized doctors available for referral of our patients close to their homes by 27.5 percent.

It is noteworthy that many more issues were ranked highly as problems for administrators than noted in responses of parents or providers. Responding administrators have taken the concerns of

the patients and the providers into consideration in their responses. A total of 10 more issues were viewed by over 10 percent of respondents as important in addition to the top three:

Incomplete information available on patients referred to our program from other providers (22.5 percent),

Appointment keeping is a problem for our program (22.5 percent),

Do not have a list of support groups available for referral of parents (20 percent),

Overall management of patient services is not coordinated among providers (17.5 percent),

Limited availability of training programs to keep our staff skills up to date (17.5 percent),

Other providers not aware of nor do they understand our services (17.5 percent),

Reimbursement rates insufficient for our services (12.5 percent),

Lack of affordable childcare for patient's children (12.5 percent),

Availability of financial coverage for our patients not clear (10 percent), and

My office staff or I are required to fill out too many forms (10 percent).

Administrators' list of problem issues can be summarized as follows:

1. Transportation for patients
2. Availability of skilled professionals within the program and for local community referrals (This includes training program availability.)
3. Patient care management issues: insufficient information from other providers, excessive paperwork
4. Financial coverage: insufficient reimbursement and information regarding financial assistance for patients
5. Affordable child care for families

Analysis of administrators' responses by geographic region demonstrated once again that issues that related to services to clients—the availability of skilled professionals, transportation, and support group information—were of greater concern (greater by 50 percent) away from the central region of the state where there is greater access to tertiary care.

Survey Summary

A comparison of issues ranked most problematic by consumers, providers, and administrators (Table 5) demonstrates that on the whole there is congruency in their choices with only a few unique issues chosen by each group. Availability of specialized physicians in areas of the state that are far away from tertiary care centers consistently appears as a concern for consumers and administrators (as “2,” next to the most critical) and for providers (as “1,” the most critical). Management issues (availability of information on patients, excessive paperwork) appear on the provider list (“2”) and the administrator list (“3”). Note that consumers ranked a related issue—their poor understanding of financial coverage—as the number one problem. Transportation is last on the list for consumers and providers but first for administrators. Financial coverage issues (including process complexity, and insufficient reimbursement) also appear first for consumers and fourth for administrators. Information and availability of parent support groups is another

major issue of concern that is mentioned in open-ended answers and is ranked highly by consumers and providers.

Table III 5: Comparison of Issues Ranked As Top Five Most Important by Consumers, Providers, and Administrators		
Consumer List	Provider List	Administrator List
Understanding financial coverage	Insufficient skilled professionals	Transportation for patients
Local availability of specialized physicians	Uncoordinated management and information regarding patient care	Availability of skilled professionals within the program and for local community referrals (including training program availability)
Child care	Lack of training programs to maintain skills	Patient care management issues: insufficient information from other providers, excessive paperwork
Access to parent support groups	Lack of information for providers regarding service availability and parent support groups	Financial coverage: insufficient reimbursement and information regarding financial assistance for patients
Transportation	Transportation for patients	Affordable child care for families

B. Education and Training Needs: Survey of Health Professionals

It was noted earlier that an alliance was formed in 1984 among the Institute for Disability Studies at the University of Southern Mississippi (IDS/USM), the Genetics Program of the Mississippi State Department of Health (MSDH) and the Division of Medical Genetics at the University of Mississippi Medical Center (UMC) to develop and implement clinical training workshops for health professionals. This alliance continued its work for ten years and by 1994 saw the need to expand and formalize genetic training programs for professionals. In preparing an application for funding for this work from the National Institutes of Health/Human Genome Project, the participants sought to obtain data on the knowledge base among professionals regarding genetics. A survey was sent to 1,500 professionals to assess the knowledge, attitudes, experiences and practice of multidisciplinary health, human service and education professionals (survey methodology, analysis and results are presented in detail in the **Appendix D**). In addition, the survey measured their perceived need and demand for genetic education. The survey results demonstrated that among 306 respondents (20 percent of survey recipients) there is a need for continuing genetic education of professionals: (1) 38 percent of respondents received their highest degree as far back as 1970-1979, 34 percent in 1980-1989 and 26 percent in the years 1990-1994; (2) 42 percent of respondents had no formal genetic education and of the 58 percent that did, only 11 percent had a full course and 46 percent had 1-2 lectures or a series of lectures; and (3) 78 percent had no formal continuing education in genetics. It was surprising that in a state with a very high proportion of its population at risk for sickle cell anemia, 75 percent of respondents reported a negligible rate of concern with genetic disease among their clients. This finding reflects a lack of knowledge about genetic disorders; 80 percent reported a need to know more about clinical genetics, genetic services and genetic testing. In reference to this lack of knowledge, 80 percent of respondents indicated their desire to receive continuing education training in genetics topics, 80 percent of respondents had never heard of the Human Genome Program before participating in this survey, 57 percent reported an interest in learning

about the Human Genome Program and 86 percent reported an insufficient knowledge of genetic resources.

A striking finding among respondents was the low level of awareness regarding the role of genetics in their particular workplaces. With the exception of one generic question regarding confidentiality safeguards, all other 19 questions on genetic issues in the workplace elicited a "not applicable" response. This finding suggests that provider agencies and schools have not formulated clear guidelines regarding these issues. The high rate of non-response to questions soliciting opinions regarding work practices and policies on genetic testing issues reinforces the conclusion that targeted professionals have not had opportunities to consider the issues and form opinions. These findings were consistent with other reports in the literature at that time.

Responses to technical questions on the survey demonstrated a need to update the majority of respondents on fundamental facts in genetics. For example, 46 percent did not know that the smallest unit of inheritance is the gene.

The alliance proposal for training workshops was funded and a curriculum was developed, tested, and presented as noted above in II F.

C. Comparing Mississippi's Current Capacity for Genetic Services to ASTHO Standards

Recognizing the responsibility of public health agencies to plan for the expansion of genetic services and their integration into the health care system, the Association for State and Territorial Health Officers (ASTHO) undertook the development of standards for the planning process. ASTHO understood that the new genetic discoveries and applications were going to be a challenge to public health providers. There is a myriad of issues that must be recognized and dealt with in the provision of genetic services:

- How can the genetic discoveries and applications be integrated into existing systems of care?
- When should genetic tests be made available, who should administer them and how can these tests be affordable for all in need?
- Decisions must be made regarding the use of genetic tests - how well do they predict disease and are there therapies available to prevent or ameliorate these diseases?
- Information regarding genetic testing must be guarded to protect patient privacy. Policies and regulations must be in place to govern the public and private sectors.
- Continuous application of new knowledge is also a responsibility of public health agencies.
- What formal framework can be used as a basis for reviewing these new challenging questions within the context of existing services and developing a specific list of needs?

ASTHO expanded the well-defined three core public health functions, assessment, policy development, and assurance, into ten essential public health service categories. ASTHO then used these services as a framework or guidance for integrating genetic services into the existing public health system. Each of the service categories is described in terms of policy goals and the services that respond to these goals. These descriptions can be used as standards for the states to measure their progress in achieving an appropriate structure and process for genetic services that are integrated into existing services. This listing of ten essential health service categories was submitted to MSDH staff for review to determine where Mississippi stood in its capacity to provide these services, identify gaps between the ASTHO standards and existing services and

specify needed strategies to fulfill the needs. Each of the ten categories is listed on the following ten pages. The gaps and strategies listed are also derived from the needs assessment described above in the consumer, provider and administrator surveys, information shown in the analysis of utilization statistics, and earlier study of genetic education needs among professionals. (The data for these tables was collected in 2002 and reflects programs and services available at that time.)

**INTEGRATING GENETICS INTO PUBLIC HEALTH: ASSOCIATION OF STATE AND TERRITORIAL HEALTH OFFICERS (ASTHO)
STATEMENT OF POLICY GOALS AND GAPS IN ESSENTIAL SERVICES IN MISSISSIPPI, 2002.**

ASTHO Description of Essential Service and Policy Goal	Current Availability of Services in Mississippi	Gaps in Essential Service in Mississippi
<p>Monitor health status to identify community health problems</p> <p>(1) Develop and maintain a strong health data collection system with the capacity to monitor genetic factors that affect health status and identify problems within the community.</p> <p>(2) Monitor community health status through vital statistics systems and on going disease surveillance with increasing emphasis on information that can help identify associations between genetic and environmental factors.</p> <p>(3) Capture clinical and laboratory information within the state generated by public and private services and report analyzed data in a useful format.</p> <p>Examine existing data sources to identify how information on genetics can be integrated and used in surveillance systems.</p> <p>Policy Goal: Ability to analyze incidence, mortality, and morbidity data to prevent genetic disease and to associate it with genetic predisposition and environmental triggers. Ability to assess community needs for genetic information and services. Enable integration of a genetics data system into existing data systems (birth defects registries, vital statistics, birth and death certificates, cancer registries).</p>	<p>(1) Data Collection Capacity:</p> <p><u>Vital Records:</u> Collection of birth and death data, linkage of records, cause of death.</p> <p><u>Newborn Screening:</u> All newborn screening data collected and reported. <u>Newborn Hearing Impairment Screening.</u> <u>Birth Defects Registry:</u> data from public and private providers collected and investigated for confirmation. <u>Breast & Cervical Cancer Screening and Early Detection Program:</u> screening, referral for diagnostic and treatment services, education and outreach programs for the public and providers, monitoring of standards for screening, enhancing state's cancer surveillance system and statewide service coordination. <u>Maternal & Child Health Needs Assessment:</u> Every 5 years statewide data collection identifies high-risk populations and prioritizes state problems, and assesses available intervention services. State performance measures and activities established annually. <u>Fetal and Infant Mortality Review:</u> A statewide but community-based process to assess and understand fetal and infant deaths is under development. <u>Pregnancy Risk Assessment Monitoring System:</u> A CDC initiative to collect data on maternal behaviors and service utilization to supplement vital records. <u>Hospital Discharge Data System:</u> in development by the MS Hospital Association.</p> <p>(2) Monitoring, data analysis and reporting capacity: The MCH Data Unit was established in 2001 to use data to enhance Maternal and Child Health outcomes, policies, and programs. Currently, the data unit has seven staff members including an MCH epidemiologist, two Principal Operations Management Analysts, a fellow/student from the Association of Public Health and the Centers for Disease Control, two interns, and a secretary. The overall responsibilities and functions of the MCH Data Unit include surveillance; assessment; monitoring; evaluation of programs; data systems and performance; and epidemiologic analyses.</p> <p>(3) Monitoring clinical and laboratory information</p> <p><u>State Public Health Laboratory</u> provides clinical lab services to public and private providers with 600,000 tests done annually including: Bacteriology, clinical chemistry, hematology, immunology, milk testing, mycology, parasitology, rabies, water microbiology and chemistry. Reports are sent back to requesting physician and nurse practitioners. These reports are for individual patients, No population based data is generated through the laboratory.</p> <p><u>MSDH Epidemiologist:</u> Collects and reports data on communicable diseases.</p> <p><u>MSDH-based MCH Epidemiologist for CDC:</u> Analyzes and reports epidemiological surveillance data.</p> <p><u>Genetic Factor Analysis:</u> Currently Birth Defects Registry is in early implementation stage. In-depth analysis of genetic disorders in the population will be developed in the future.</p>	<p>Improvement of data collection capacity for mother and child population currently established as one of top state priorities.</p> <p>Needed a centralized capacity for analysis of Birth Defects Registry data, laboratory data, epidemiological and environmental hazard reports, hospital discharge data and vital records to determine trends, patterns and report to Health Officer for planning.</p>

**INTEGRATING GENETICS INTO PUBLIC HEALTH: ASSOCIATION OF STATE AND TERRITORIAL HEALTH OFFICERS (ASTHO)
STATEMENT OF POLICY GOALS AND GAPS IN ESSENTIAL SERVICES IN MISSISSIPPI, 2002.**

ASTHO Description of Essential Service and Policy Goal	Current Availability of Services in Mississippi	Gaps in Essential Service in Mississippi
<p>Diagnose and investigate health problems and health hazards in the community</p> <p>(1) Conduct public health research into the causes of health problems including relevant genetic factors to better understand prevention opportunities. Such research is done through newborn screening and outbreak investigations to cancer prevention education.</p> <p>(2) Collaboration between health agency and environmental agencies to address environmental factors that may interact with genes to cause disease. (3) Identification of behavior modifications to minimize disease. (4) State health agency epidemiologists and social behavioral scientists should incorporate genetic information into their work.</p> <p>Policy Goal: Identify genetic risk factors to increase the opportunity for early intervention and disease prevention. A health promotion plan that empowers citizens to reduce risk of disease using genetic information exists. Train personnel to investigate genetic health hazards and create behavior change programs.</p>	<p>MSDH processes in place that respond to each of the points in the description in left column:</p> <p>(1) Research into causes of health problems: No planning for these activities.</p> <p>(2) Collaboration between health agency and environmental agencies: Unknown</p> <p>(3) Identification of behavior modifications to minimize diseases: Unknown</p> <p>(4) Incorporating genetic information into health services: Unknown</p>	<p>Capacity to translate results of integrated data analysis to identify genetic risk factor and develop appropriate plans for intervention. This capacity includes trained staff and equipment for analysis of genetic health hazards and for intervention planning.</p>

**INTEGRATING GENETICS INTO PUBLIC HEALTH: ASSOCIATION OF STATE AND TERRITORIAL HEALTH OFFICERS (ASTHO)
STATEMENT OF POLICY GOALS AND GAPS IN ESSENTIAL SERVICES IN MISSISSIPPI, 2002.**

ASTHO Description of Essential Service and Policy Goal	Current Availability of Services in Mississippi	Gaps in Essential Service in Mississippi
<p>Inform, educate, and empower people about health issues The state health agency should educate the public on genetics and health. The general public as well as key policy makers will need basic information about genetics and its relationship to maintaining good health. These materials should be culturally relevant and made easily available to underserved populations. Additionally, general education materials will be needed for low literacy levels. Social marketing campaigns for preventable diseases should include clarifications about when genetics is a major factor and when it is not. Policies should allow the public the option to obtain any available genetic information about themselves without fear that the information will be used against them.</p> <p>Policy Goal: The general public and policymakers are well informed about genetics and its impact on health. Individuals are provided consistent information through a range of focused health education programs so that informed decisions regarding genetics can be made. Residents also understand how certain environmental exposures increase risk of disease, and how to reduce their risk by modifying behavior or reducing exposure.</p>	<p><u>MSDH Information provided:</u></p> <ul style="list-style-type: none"> • To public and private providers for women in early stage of pregnancy regarding availability of maternal serum alpha-fetoprotein, human chorionic gonadotropin, and unconjugated estriol testing. • Also to all new parents through local providers regarding newborn screening options. • The Division of Health Promotion provides health education and information programs to help public officials, community groups, school administrators, employers/worksites, health professionals and families make the best possible health decisions. The Division works on the local level to promote physical activity, nutrition, comprehensive school health, injury and violence prevention and prevention and control of cardiovascular disease, diabetes and arthritis to improve the health of all Mississippians. The Health Promotion Clearinghouse provides resources and research about science-based programs to improve health. The Division conducts the Youth Risk Behavior Survey and disseminates results to decision-makers and agencies serving youth. Data from this survey and the Behavior Risk Factor Surveillance System guide operational objectives for local interventions. <p><u>MSDH Toll-Free Lines:</u> are publicized through newsletters published by the American Academy of Pediatrics/MS Chapter, brochures, posters, and Teen Help Card. These lines include the following:</p> <ul style="list-style-type: none"> • Provides assistance to clients seeking information about MCH services, family planning, Medicaid, WIC, and other services. Encourages early entry into prenatal care and link private and public providers. • Provides information for Genetics/Early Intervention • HIV/AIDS • CMP - Children's Medical Program <p><u>March of Dimes Information/Education Programs:</u> provide information and education on folic acid through community organizations around the state through grants funded by the Mississippi Chapter of the March of Dimes.</p> <p><u>Consumer Health Education Center Project:</u> University Hospitals and Medical Library initiative to provide improved health information to communities served by the University Medical Center. Also, health information is available at the program's statewide Website (chec.library.umc.edu).</p>	<p>Presently the Division of Health Promotion, Mississippi State Department of Health is not provided any funds, federal or state, to educate the public on genetics and health within the state. Funds are needed to be begin strategic planning process to address genetic education for all Mississippians. The planning process should also focus on infrastructure development - that is the development of a cadre of teachers and a curriculum. These efforts should also include social marketing techniques for the diverse populations within this state.</p>

**INTEGRATING GENETICS INTO PUBLIC HEALTH: ASSOCIATION OF STATE AND TERRITORIAL HEALTH OFFICERS (ASTHO)
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ASTHO Description of Essential Service and Policy Goal	Current Availability of Services in Mississippi	Gaps in Essential Service in Mississippi
<p>Mobilize community partnerships at the state and local levels to identify and solve health problems The state health agency should identify public and private community programs and partners interested in working collaboratively to promote effective and efficient decision-making about genetics. Within the state health agency, program partnerships with segments of the community will provide the basis for broad input on public health issues associated with genetics. These will need to be coordinated as broad policies and practices are implemented. Through partnerships, the state health agency will be able to use key community peer leaders to inform citizens of beneficial genetic information. Partnerships also may focus on securing needed legislation for issues. Partnership members should represent the diversity of the state or community, be accountable to the community they represent, and have equal levels of decision making.</p> <p>Policy Goal: By expanding partnerships and fostering new collaboration, state health departments will communicate more effectively with community members using the foundation of trust. The participation of a variety of public and private entities will ensure that programs, policies, and other health department efforts are relevant to the target audience.</p>	<p>State and Local Level: MSDH Partnerships/agreements in place with other entities provide opportunities for identification of health care access issues and collaboration on services at state and local level including the following:</p> <ul style="list-style-type: none"> • prenatal testing through University Medical Center, • treatment of hemophiliac patients at University Medical Center • newborn screening through all hospitals • diagnostic and treatment services through satellite Genetic Clinics in conjunction with University Medical Center. Local MSDH Coordinators work with local providers to facilitate follow up services in the community, • coordination of local substance abuse, domestic violence and rape programs around the state, • mental health services coordinated by local county health departments and mental health centers. Regional mental retardation centers to expand capacity for local family-centered care. • Early Intervention Program for comprehensive, coordinated services at local level. Program guidance is provided by state-level Interagency Coordinating Council bringing together parent representatives, agencies (Mental Health, Education and Human Services), universities, service providers, and, local interagency councils facilitate the process throughout the state. • case management and day care for children with disabilities through Dept. of Human Services. • reproductive health contracts with community health centers and universities/colleges. • WIC services through community health centers • perinatal service planning and provider education with community health centers • advocacy, studies, recommendations through the Infant Mortality Task Force. • Mississippi Access for Rural Care project funded by the Robert Wood Johnson Foundation provides coordination of activities, services, issues, and technical assistance opportunities related to rural health services through MSDH and the Mississippi Primary Health Care Association (MPHCA), which serves as the lead agency. <p>Children's Medical Program - the state's Children with Special Health Care Needs (CSHCN) program at MSDH established an Advisory Council, including parents, physicians, hospitals, physical therapists and social workers, to facilitate local service coordination for children with disabilities.</p>	<p>These partnerships and agreements are in place for a wide variety of services with a diverse array of public and private providers. However, there is no organized effort at present to use these relationships to enhance communication regarding genetic services and dialogue regarding needed legislation.</p>

**INTEGRATING GENETICS INTO PUBLIC HEALTH: ASSOCIATION OF STATE AND TERRITORIAL HEALTH OFFICERS (ASTHO)
STATEMENT OF POLICY GOALS AND GAPS IN ESSENTIAL SERVICES IN MISSISSIPPI, 2002.**

ASTHO Description of Essential Service and Policy Goal	Current Availability of Services in Mississippi	Gaps in Essential Service in Mississippi
<p>Develop policies and practices that support individual and community health efforts The state health agency should provide the leadership necessary for the development of public policies and programs that provide guidance on applying genetic information to health promotion and disease prevention. The state health agency must develop and use standards for integrating genetics into public health practices that reflect the community standards, values, and needs. The state health agency should use a strategic planning process to develop a comprehensive plan to incorporate genetics into the state health agency.</p> <p>Policy Goal: State policies and programs that appropriately apply genetics information to improve individual and community health. A strategic plan to guide the integration of genetics into public health practice.</p>	<p>AUTHORITY: <u>General Enabling Legislation:</u> Section 41-3-15 Mississippi Code of 1972, Annotated, provides that the State Board of Health shall have the authority in its discretion to establish programs to promote the public health, to be administered by the State Department of Health. <u>Infant Mortality Task Force</u> provided through the Mississippi Code, Annotated, Section 41-89-1 through 41-89-5. Funding through the MSDH. <u>Agreements with Other Agencies:</u> entities that serve maternal and child health patients through contractual or cooperative agreements with the MSDH include the Mississippi Division of Medicaid and the University of Mississippi Medical Center. <u>Perinatal Regionalization:</u> is provided through the Mississippi Code 41-81-1, and 41-81-3 of 1987 and authorizes MSDH to coordinate the development and the implementation of a regionalized system of perinatal services. MSDH is authorized to enter into contracts with and provide grants to health care providers to implement a statewide regionalization program. <u>Perinatal High Risk Management:</u> establishment at the Division of Medicaid was authorized in amended section 43-13-117 Mississippi Code of 1972. <u>Newborn Screening and Follow up:</u> has been authorized and amended through Sections 41-21-201 through 41-21-203 of the Mississippi Code of 1985, 41-21-1 through 41-24-5 of the Mississippi Code of 1988 and 1991, and most recently amended Section 41-21-203 Mississippi Code of 1985. MSDH is authorized to adopt rules and regulations to carry out screening for hypothyroidism, and phenylketonuria, galactosemia and hemoglobinopathies and educate the public on these disorders. Physicians attending newborns are held responsible for ensuring newborns receive the screening tests as described. Recent legislation authorizes testing for congenital adrenal hyperplasia as part of the newborn screening program. Physicians attending a newborn child are required to notify the parents there are newborn screening tests available that may be given to the child in addition to required tests. MSDH was required to provide physicians with information regarding these additional tests. <u>Early Intervention for Infants and Toddlers:</u> Authorizes in Sections 41-87-1 through to 41-87-19 the development of a statewide, comprehensive coordinated multidisciplinary, interagency system of early intervention services that are family centered and community based for all eligible infants and toddlers (and their families) who are at risk for developmental delay. <u>Birth Defects Registry:</u> Section 41-21--205 of the Mississippi Code established a birth defects registry and authorized MSDH to adopt rules to govern the operation of the registry program and authorized the department to conduct certain investigations. The registry has access to demographic data of every newborn in the state within 6 months of birth.</p>	<p>Legislative authority enables program development by MSDH in general and in newborn testing, data collection, and other maternal and child health services. A plan is needed to integrate genetics into the public health service system. Such a plan is currently under development.</p>

**INTEGRATING GENETICS INTO PUBLIC HEALTH: ASSOCIATION OF STATE AND TERRITORIAL HEALTH OFFICERS (ASTHO)
STATEMENT OF POLICY GOALS AND GAPS IN ESSENTIAL SERVICES IN MISSISSIPPI, 2002.**

ASTHO Description of Essential Service and Policy Goal	Current Availability of Services in Mississippi	Gaps in Essential Service in Mississippi
<p>Enforce laws and regulations that protect health and ensure safety The state health agency should provide leadership to secure an adequate legislative base and the oversight authority for genetic testing and related clinical services having as the goal the protection of the public from inappropriate use of genetic information, research, or services. Genetic legislation and regulation also should address the effectiveness, accessibility, and quality of genetic tests and services. Once legislation is enacted, the state health agency should establish policies and regulations for monitoring compliance and actively enforce statutes and regulations. Issues needing legislative leadership from state health agencies are: prohibitions against insurance discrimination, employment discrimination, disclosure of genetic/medical information; informed consent requirements; property rights of personal genetic information; and regulation of clinical professions providing genetic services such as counseling, conduct of genetic research.</p> <p>Policy Goal: Public health should participate in the development of legislation, statutes, and regulations that provide for the optimal use of data while protecting the privacy of clients and consumers.</p>	<p>Enforcement is possible for some but not all current laws and regulations that protect health and ensure safety. Laws and regulations that impact on genetic services available for existing services. Expansion of these services will require review and discussion regarding state laws to govern these expanded services.</p>	<p>Needed: a plan for consistent enforcement of laws and regulations and development of new legislation regarding expanded genetic services.</p>

**INTEGRATING GENETICS INTO PUBLIC HEALTH: ASSOCIATION OF STATE AND TERRITORIAL HEALTH OFFICERS (ASTHO)
STATEMENT OF POLICY GOALS AND GAPS IN ESSENTIAL SERVICES IN MISSISSIPPI, 2002.**

ASTHO Description of Essential Service and Policy Goal	Current Availability of Services in Mississippi	Gaps in Essential Service in Mississippi
<p>Link people to health services including genetic services, and assure the provision of health care when otherwise unavailable</p> <p>The state health agency should provide the leadership necessary to ensure that (1) appropriate services are available for preventing diseases. Where necessary, states should establish the capacity for the provision (2) of specific genetic services and ensure the availability and accessibility of intervention strategies that incorporate (3) genetic information to improve health and prevent disease. The state health department should capitalize on new genetic discoveries to improve the public's health and to integrate genetic information to enhance existing programs. This may include identification of funding sources (4) for provision of individual services as well as funding necessary to ensure that qualified personnel and facilities are available and accessible to the public. Services should be (5) community-based, culturally sensitive and referrals readily available within mainstream health care services to individuals needing or desiring genetic services. These services include those aimed at prevention, health education, and primary care and specialty services.</p> <p>Policy Goal: High quality, culturally competent services, including genetic services, are available to those who need or desire them. High quality, clinically valid genetic tests are available to the public. Genetic information and services are culturally competent and effective in improving health.</p>	<p>(1) <u>MSDH capacity to serve the population</u> is not only through its own network of 81 county health departments which provide a variety of services but also through the numerous partnerships and agreements in place with a variety of public and private providers (as shown on page 6) to enhance those basic services. Prevention, diagnosis, follow up care are all available both through the MSDH county health departments and also through its public and private provider collaborations.</p> <p>(2) <u>Genetic Services</u>: A comprehensive statewide program including screening, diagnosis, counseling, and follow up of a broad range of genetic related disorders. Seven genetics satellite clinics and five sickle cell satellite clinics are strategically located in the state. Services include:</p> <ul style="list-style-type: none"> • hemoglobinopathy services (screening, education, follow-up and treatment) are available through the Sickle Cell Disease Program of MSDH with screening and counseling throughout the state. • clinical genetics (genetics clinics, education and treatment) • newborn screening/birth defects registry • case management and provider education to over 70 hospital nurseries/laboratories and 120 health departments. <p>Expansion of newborn screening as described on page 7 adds Congenital adrenal hyperplasia to the required list of phenylketonuria, galactosemia, congenital hypothyroidism and hemoglobinopathies. Additional tests will be described to parents and made available by the physician attending the newborn. The MS Muscular Dystrophy Association provides genetic screening and counseling in three locations.</p> <p>(3) <u>The MSDH Genetic Advisory Committee</u> provides ongoing advice on new genetic information and its applicability to MSDH services.</p> <p>(4) Funding sources for genetic services recipients and work force training. <u>One Step Career Centers at the state's eight Community Colleges</u> via the Mississippi Workforce Education Act of 1994 provide workforce training opportunities. <u>WIN Job Centers</u> in every county offer federally funded job training through Workforce Investment Act funding.</p> <p>(5) Services for prevention, health education and primary and specialty care are linked, accessible, responsive to individuals needing genetic services.</p> <p><u>Mississippi Dept of Rehabilitation Services</u> provides a variety of services to individuals with disabilities and their families including medical assistance, occupational therapy, counseling, educational assistance, job training and placement.</p>	<p>Integration of genetic services throughout this public/private system is under study with the Genetic Services Planning Project. Availability of funds is a critical issue in integrating genetic services into public and private health services, developing a work force that is qualified to provide such services and building a data system to support integration of services.</p>

**INTEGRATING GENETICS INTO PUBLIC HEALTH: ASSOCIATION OF STATE AND TERRITORIAL HEALTH OFFICERS (ASTHO)
STATEMENT OF POLICY GOALS AND GAPS IN ESSENTIAL SERVICES IN MISSISSIPPI, 2002.**

ASTHO Description of Essential Service and Policy Goal	Current Availability of Services in Mississippi	Gaps in Essential Service in Mississippi
<p>Assure a public health and personal health care workforce competent in genetics The state health agency should ensure that present and future health professionals have training and skills in the appropriate use of genetic information to promote health and prevent disease. The agency also should work with academic institutions to ensure that genetics is incorporated into the public health educational system and provide continuing education opportunities in genetics to the public health workforce. The state health department should work with professional organizations to ensure that all health care providers, especially primary care providers, have continuing education opportunities in genetics and credit for participation in those programs. Health departments also should participate in establishing genetics competencies.</p> <p>Policy Goal: A public health workforce competent in genetics exists and is maintained. Public health practitioners and health care providers have access to credit bearing continuing education opportunities in genetics.</p>	<p>UMC Schools of nursing, medicine, dentistry, and health-related professions (physical therapy, occupational therapy, speech therapy, etc.). Nursing education programs at the associate, baccalaureate, master's, and doctoral degree levels through UMC and other colleges and universities. There are a total of 23 undergraduate and five graduate nursing education program. State community colleges offer programs leading to associate degrees as physical and occupational therapy assistants, and other health related professions.</p> <p>Describe extent of genetic training included for major professional training programs for the baccalaureate degree: unknown</p> <p><u>IDS/UAP Genetics Information Survey of Professionals:</u> results illustrate lack of genetic education at the baccalaureate and postgraduate levels.</p> <p><u>IDS/UAPGenESES Project:</u> Through this project funded by the National Institutes of Health 1996-1999, IDS in collaboration with MSDH and UMC developed and implemented a model comprehensive program for genetics education for health, education and human services professionals. Education content of workshops attended by 1000 professionals provided information about recent advances in genetics from the Human Genome Project, demonstrated the clinical relevance of research outcomes, facilitated a dialogue on the ethical, legal, and social implications of genetic outcomes for professionals, patients and their families and communities, and assisted providers in accessing information and referral sources.</p> <p><u>IDS/UAP Delta Project:</u> Building on the success of the GenESES Project, IDS in continued collaboration with MSDH and UMC, has written a second proposal to the NIH to create a series of on-line genetic continuing education courses for state professionals using Web-CT, Web casting (digital video archives), desktop video conferencing and other television and computer technologies.</p> <p><u>Dietetic Education:</u> CSHCN program nutrition staff work with university affiliated nutrition education programs in state to develop and implement community-based programs for senior or graduate nutrition/dietetic students to prepare them to work with special needs populations.</p>	<p>Coordination of education of a health care workforce competent in genetics at the baccalaureate level and continuing with postgraduate training based on the GenESES Project workshop model.</p> <p>There is a need for a detailed study of genetic education in state's professional training programs and post graduate continuing education programs to assure policy goal is met.</p>

**INTEGRATING GENETICS INTO PUBLIC HEALTH: ASSOCIATION OF STATE AND TERRITORIAL HEALTH OFFICERS (ASTHO)
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ASTHO Description of Essential Service and Policy Goal	Current Availability of Services in Mississippi	Gaps in Essential Service in Mississippi
<p>Evaluate effectiveness, accessibility, and quality of personal and population-based health services, including genetics</p> <p>The state health agency should assure that a system is in place to provide ongoing evaluation of the impact of genetic information, the effectiveness, the accessibility and the quality of genetic tests and population-based health services. Quality of services, personnel providing them, cultural competency of the services, use of surveillance and population-based epidemiological studies are important components of evaluation. Evaluation of policies and quality of genetic tests is needed prior to any considerations for population-based genetic testing. The health outcomes of individuals who participated in genetic services such as testing or pharmacogenomics should be evaluated to determine the effectiveness of genetics in improving health. Ongoing monitoring of the utilization of community services, e.g., genetic testing services, also is necessary to develop a comprehensive evaluation of the impact of genetics in public health. Communication and information dissemination will be necessary to provide timely and accurate information to the general public and professionals in order to enhance their basic knowledge about genetics, genetic screening, counseling and comprehensive services.</p> <p>Policy Goal: Programs, services, testing screening, and treatments that include up-to-date relevant genetic information are effective and accessible.</p>	<p><u>Maternal & Child Health Needs Assessment:</u> Statewide data collection to identify high-risk populations and prioritize state problems done every 5 years. Also conduct assessment of available intervention services. State Performance Measures and activities established and monitored annually.</p>	<p>Formal mechanism developed to facilitate the analysis by a professional panel of all testing and screening currently in place.</p>

**INTEGRATING GENETICS INTO PUBLIC HEALTH: ASSOCIATION OF STATE AND TERRITORIAL HEALTH OFFICERS (ASTHO)
STATEMENT OF POLICY GOALS AND GAPS IN ESSENTIAL SERVICES IN MISSISSIPPI, 2002.**

ASTHO Description of Essential Service and Policy Goal	Current Availability of Services in Mississippi	Gaps in Essential Service in Mississippi
<p>Research for new insights and innovative solutions to health problems</p> <p>The state health agency should identify research findings that are ready to be incorporated into the public health system. On-going studies of the impact of gene variants on human health and the related environmental risk factors, the economic and ethical implications of genetic information, and the utilization and quality of genetic tests and services should be conducted.</p> <p>Policy Goal: Relevant genetic information is continually updated and incorporated into the public health infrastructure.</p>	<p>No formal coordinated mechanism in place to conduct such research.</p>	<p>Establish a mechanism for yearly review and updates of research findings. Such a process could be undertaken through the university.</p>

D. Summary of Assessments and Studies

The information collected in the needs assessment is summarized on the table that follows. The gaps in essential services are shown and were presented to the State Health Officer's Task Force on Genetic Services for their discussion. Results of that discussion are shown in summary form in Section E.

INTEGRATING GENETICS INTO PUBLIC HEALTH: SUMMARY OF ASSOCIATION OF STATE HEALTH OFFICERS (ASTHO) STATEMENT OF POLICY GOALS AND GAPS IN ESSENTIAL SERVICES IN MISSISSIPPI, 2002.

ASTHO Description of Policy Goal	Gaps in Essential Service in Mississippi
1. Ability to analyze incidence, mortality, and morbidity data to prevent genetic disease and to associate it with genetic predisposition and environmental triggers. Ability to assess community needs for genetic information and services. Enable integration of a genetics data system into existing data systems (birth defects registries, vital statistics, birth and death certificates, cancer registries).	<ul style="list-style-type: none"> • A hospital discharge data system to provide morbidity and mortality patterns • Enhanced data collection capacity for mother and child population • Centralized capacity for analysis of Birth Defects Registry data, laboratory data, epidemiological and environmental hazard reports, hospital discharge data and vital records to determine trends, patterns and report to Health Officer for planning.
2. Identify genetic risk factors to increase the opportunity for early intervention and disease prevention. A health promotion plan that empowers citizens to reduce risk of disease using genetic information exists. Train personnel to investigate genetic health hazards and create behavior change programs.	<ul style="list-style-type: none"> • Capacity to translate results of integrated data analysis to identify genetic risk factor and develop appropriate plans for intervention. This capacity includes trained staff and equipment for analysis of genetic health hazards and for intervention planning.
3. The general public and policymakers are well informed about genetics and its impact on health. Individuals are provided consistent information through a range of focused health education programs so that informed decisions regarding genetics can be made. Residents also understand how certain environmental exposures increase risk of disease, and how to reduce their risk by modifying behavior or reducing exposure.	<ul style="list-style-type: none"> • Capacity to develop a strategic planning process to address genetic education for all Mississippians. This capacity includes a trained cadre of teachers and a curriculum that is culturally competent and is aimed at understanding of environmental hazards.
4. By expanding partnerships and fostering new collaboration, state health departments will communicate more effectively with community members using the foundation of trust. The participation of a variety of public and private entities will ensure that programs, policies, and other health department efforts are relevant to the target audience.	<ul style="list-style-type: none"> • Organized effort using existing partnerships and agreements between the health department and various public and private entities to enhance communication regarding genetic services and dialogue regarding needed legislation. • Parent support groups accessible throughout the state and information on these groups available to all providers
5. State policies and programs that appropriately apply genetics information to improve individual and community health. A strategic plan to guide the integration of genetics into public health practice.	<ul style="list-style-type: none"> • Planning to modify current legislative authority to integrate genetics into the public health service systems. Such a plan requires extensive public dialogue and education.
6. Public health should participate in the development of legislation, statutes, and regulations that provide for the optimal use of data while protecting the privacy of clients and consumers.	<ul style="list-style-type: none"> • Planning for consistent enforcement of laws and regulations and development of new legislation regarding expanded genetic services
7. High quality, culturally competent services, including genetic services, are available to those who need or desire them. High quality, clinically valid genetic tests are available to the public. Genetic information and services are culturally competent and effective in improving health.	<ul style="list-style-type: none"> • Integrated & coordinated genetic services throughout the state's public and private health systems with a secure information system. • National standards for genetic testing are met; these services are accessible to the diverse population • Continuing monitoring and evaluation of the process and outcome of integrated genetic services. • Financial support options identified for parents and providers • Financial support options expanded • Child care and transportation assistance enhanced.
8. A public health workforce competent in genetics exists and is maintained. Public health practitioners and health care providers have access to credit bearing continuing education opportunities in genetics.	<ul style="list-style-type: none"> • Capacity for coordinated genetic education and training in the state's professional training programs at the baccalaureate and postgraduate levels. Such programs undergo continual study and revision to include new knowledge.
9. Programs, services, testing screening, and treatments that include up-to-date relevant genetic information and are effective and accessible.	<ul style="list-style-type: none"> • Formal mechanism to facilitate the analysis by a professional panel of all testing and screening currently in place to assure tests are appropriate, effective and accessible.
10. Relevant genetic information is continually updated and incorporated into the public health infrastructure	<ul style="list-style-type: none"> • Annual review and updates of research findings. Such a process could be undertaken collaboratively among UMC, MSDH and professional associations.

E. Summary of Task Force Discussion on Gaps in Genetic Services

Information collected through the assessment process included the following:

- The descriptions of existing services
- Statistics on utilization and costs of genetic services
- Descriptions of current genetic educational and training programs
- Surveys of consumers, providers and administrators on existing services
- Surveys of professionals regarding their knowledge base on genetics
- The review of Mississippi's capacity to comply with the standards established through ASTHO for enhancing and integrating genetic services

This information has been summarized and the gaps in services identified. The gaps were grouped into five action/issue categories each of which included activities aimed at closing gaps. At this point in the planning process, the State Health Officer's Task Force on Genetic Services was re-convened and asked to provide input in a form that summarized the five action categories. Comments, questions and suggestions from the Task Force were summarized on this form and shown on the five pages that follow.

Issue #1: Enhanced information system for mother and child population: Data resources exist in various agencies - public and private. What additional data are needed and how do we integrate these for analysis and application? Existing Data Unit at MSDH requires additional dedicated staff to oversee this three-part effort: A team is needed that determines existing data resources, identifies gaps, specifies new resources that are needed, and develops a data integration process and analysis plan.	
Gaps in Essential Genetic Service in Mississippi	Task Force Summarized Comments on Identified Gaps in Essential Services
A. <u>Enhanced data collection capacity:</u> A variety of data resources are available at MSDH - what other public/private data resources exist for this population and what data needed? Staff needed to gather answers to this question, i.e., a data needs assessment. What timeline is reasonable to accomplish this?	<p>Need a data manager position for MSDH/Genetics. Suggest a 5-year plan.</p> <p>Include a data set for adult-onset disorders; need to take into account an aging population with longer lifespan. Consider impact on family members in the data collected. Need data management position. Logging in on patient admission. Where is the starting point for data entry? At the patient level: the Care manager coordinates data gathering as well as care.</p>
B. <u>Enhanced centralized capacity for data linkage and integration:</u> Staff needed to plan data integration across agencies, and where possible private sector resources; issues of security - compliance with HIPPA - must be addressed; hardware and software also needed for this task. Where should this staff/team be housed? What timeline is reasonable to accomplish this?	<p>Create an interagency team. Essential but cannot implement unless required/mandated. Difficult to integrate multiple systems and meld public with private sectors due to HIPPA concerns Ask: what is minimal information needed, who needs it and why. House at MSDH/Genetics with an indefinite time line. Just linking Medicaid and MSDH systems may take 2-3 years. Consider issues of hardware & software compatibility, and the fact that each agency is updating its systems. Examples exist in MA and MI. This will be a very long-range process for MS. Must include HIPPA in planning (10/03 start time) with new privacy requirements. Data integration and analysis complex so need qualified staff with biostatistics and epidemiology expertise. Assure mechanism in place to match for unduplicated reporting. Involve multiple agencies and the use of memoranda of understanding to promote integration. Process of integration: deliberate and thoughtful. Catalogue what we have and then determine where expansions are needed. Link with Jackson Heart Study data.</p>
C. <u>Enhanced capacity to translate results of integrated data:</u> Data analysis to identify genetic risk factors and develop appropriate plans for intervention. Staff must have expertise to understand genetic health hazards and implement intervention planning. Staff to work with other public and private entities during analysis and intervention planning. What types of structure and process are needed to implement?	<p>Place within MSDH epidemiological and geneticist resources. May take 5-10 years because first must get information we now have and analyze it before we move on. Include liaison with USDA and MSDA. "Data analysis" here is meant to be epidemiological analysis but assure that the data used is accurate. Economic data analysis needed by diagnostic codes since costs and reimbursements differ by diagnosis. And project costs as lifespan expectation is lengthened.</p>

Issue # 2: Integrated and coordinated genetic services must be accessible throughout the state's public and private health systems. Maintenance of quality and adherence to standards, are essential components of these services. A dedicated structure and process needed to accomplish with sufficient staff for planning, implementation and maintenance of these services.	
Gaps in Essential Genetic Services in Mississippi	Task Force Summarized Comments on Identified Gaps in Essential Services
A. <u>Provision of integrated & coordinated genetic services</u> Development of state plan is first step to achieving goal. Plan developed to be reviewed by advocacy groups. How to monitor plan implementation? Need establishment of permanent interagency genetics advisory group to oversee long- term plan for genetic services.	High priority: interagency group of advisors should set goals and work with MSDH Data Management division to oversee implementation of integration of services. Such a plan should have measurable outcomes/goals each year with quarterly reports. House at MSDH/Genetics. Should include parents in planning process. In this process use a flexible plan/process since genetics is a constantly evolving field. Such a plan cannot stand in isolation - must be incorporated into total system of care. UMC and MSDH need to work together to ensure there is no duplication of services. Consider congenital disorders among adults and new service demands. Pediatric patients with genetic conditions now growing into adulthood - e.g., treatment for pregnant women with PKU. The importance of early intervention for sickle cell disease. Down syndrome among adults; how to integrate when north and south MS services relate to TN and AL and LA?
B. <u>Quality assurance issues:</u> How to maintain continuing monitoring and evaluation of the process and outcome of integrated genetic services. Oversight must include assurance of access to services by diverse population and adherence to national standards for genetic testing. Need dedicated staff to conduct record reviews, compliance reviews with standards for lab testing and patient follow-up. Regular contact needed with advocacy groups for consumer input.	Annual review by the Advisory Group to focus on QA. AAP source for national standards? There are no national standards yet. A minimum set of tests should be available. Record reviews are costly but Q/A for services is needed. There are existing programs to review quality - need to integrate this existing effort. Hospitals must have a compliance function now - it may be possible to add record and lab compliance activities to it. Confidentiality is a must. Base this effort in the University but how to include north and south of MS. Assuring quality means providers must know current practice guidelines, where to refer and get expert consultation - create a Center for Updated resources/information.
C. <u>Planning for consistent enforcement of laws and regulations:</u> Enforcement of compliance requires ongoing review of medical records and consumer queries/complaints. Experience with enforcement applied to development of new legislation for expanded genetic services.	No punitive measures available nor are these recommended, rather use education and constant surveillance. Also use consumer complaint hotline to assure compliance. Consistency may be based on state laws that are regulated by MSDH.

Issue # 3: Family support services are found across multiple public and private entities; eligibility information about these must be integrated for enhanced consumer and provider access. Such an enhanced information system provides a first step to understanding current options for financial support. Widespread use will identify statewide limitations and suggest opportunities for expansion through legislative and private initiatives. This ambitious work plan requires dedicated staff with expertise and, close work with advocacy groups and providers. Where would this work be implemented?

Gaps in Essential Genetic Services in Mississippi

Task Force Summarized Comments on Identified Gaps in Essential Services

A. Financial support options identified for parents and providers: Staff with hardware and software resources needed to design and develop an interactive data bank to hold information on financial support options, eligibility requirements, contacts. Such information must be updated regularly to be useful. The data bank would be accessible on-line to consumers and providers. Where to house this project?

Currently providers and staff spend too much time assisting with financial support information so need better system. Many families need long-term coordinators to assist but these staff need ongoing training too. A computerized system with a web page would require the consumer to enter income, etc and will get list of eligible services, amounts and requirements. The challenge is how to ensure equal access by the most needy to support options.

The data bank can be a joint effort of MSDH and DHS.

B. Financial support options expanded: Experience with data bank will indicate where limitations exist. Consumers and providers also queried to obtain information on limitations. A needs list for expanded support options developed for exploration with advocacy groups, legislative contacts and private charitable groups.

Begin with a document - reader-friendly - that lists resources in MS.

Less important initially.

C. Child care and transportation assistance enhanced: An example of an identified area of need throughout the state. This assistance can be an immediate priority for staff to explore options, understand variability across the state, query consumers regarding preferences for resolution and development of a plan.

Transportation is essential in MS but variable needs in different communities; consider non-traditional resources. Consider the use of satellite clinics to ease transportation barriers. Medicaid continues to provide non-emergency transportation for its beneficiaries. An information clearinghouse should include this information in it. Since consumers ranked these services 3rd and 4th we may be able to put this on the back burner? Reference HeadStart transportation services for ages 3-5 which are available with few financial restrictions. Reference AIDS programs for childcare, transportation through HHS Ryan White - are there other such sources for genetic disorders. Involve the Depts. of Transportation and Education, and HeadStart

Issue #4: Facilitate development of legislative initiatives for genetic services with consumer and provider input and support. Process requires education of and dialogue among consumers, providers, and legislators, and, understanding of current system of genetic services. How to implement process?	
Gaps in Essential Genetic Services in Mississippi	Task Force Summarized Comments on Identified Gaps in Essential Services
A. <u>Capacity to develop a strategic planning process to address genetic education for all Mississippians.</u> This capacity includes a trained cadre of teachers and a curriculum that is culturally competent and is aimed at understanding of environmental hazards. Implementation will require dedicated staff to initiate planning process with outside advisory input of consumers, providers and educator specialists. Timeline for development?	Laudable but difficult because disease processes are rare and very distinct. Greatest challenge is getting public to understand how important genetics is. Most do not take it seriously til there is direct personal experience. Must educate public regarding false medical soundbites so prevalent in the media, e.g., the so-called 'hazards of immunizations'. March of Dimes and other sources have initiated strategic planning. This process is costly and has an indefinite endpoint. How to measure its success? Suggest a private group take on this process in collaboration with public providers. Suggest give it a one-year time line.
B. <u>Parent support groups accessible throughout the state :</u> Consortium of advocacy groups facilitates development and promotion of expanded parent support network. Group disseminates information to public and providers. Work of consortium sponsored and supported by a public or private agency?	This should be an MSDH-MODimes effort: through MSDH clinics, MODimes resources and web based. Work with the media to get more news stories, ads, and public service announcements to increase awareness of genetics. Public awareness and activism will drive lawmakers. Consumers put this 4 th on their list – don't have time for meetings? Suggest this belongs in a public agency. Consider that some parents may not want to participate!
C. <u>Communication between and among consumers, public and private providers and legislators regarding legislative issues in genetic services.</u> Facilitate process through an interagency task force with dedicated staff to develop enhanced linkages and dialogue? Where is most effective location for such staff?	Cannot lobby but an interagency task force could help legislature when asking for specific input (as in recent effort for supplemental screening). Identify needs for communication - think of resources and efforts to evaluate. Can house this effort at Institute for Disability Studies/Jackson.

Issue # 5: Provider training and education is a critical link to maintenance of standards in testing and patient care. Training provides opportunities for updating with new information and application to consumer services. New information also linked to public and legislator education programs. This work requires dedicated staff and support resources.

Gaps in Essential Genetic Services in Mississippi	Task Force Summarized Comments on Identified Gaps in Essential Services
<p>A. <u>Enhanced capacity for provider education and training:</u> A statewide initiative for coordinated genetic education and training is needed in the state's professional training programs at the baccalaureate and postgraduate levels. Such programs undergo continual study and revision to include new knowledge. Where can this work be accomplished?</p>	<p>Develop guidance on what providers know now and then given them a resource on the web. Difficult to implement as we have limited ability to impact established programs. Locate effort in the universities. The survival of children into adulthood with congenital anomalies is a growing training challenge. Educate adult specialists on relevant clinical issues for sickle cell, cystic fibrosis, PKU, thyroid disease, diabetes I and II, adult congenital heart disease, Downs syndrome survivors, obesity. New clinical findings to be integrated into genetics training. Additional grants needed for such training. USM Nursing included a required course on genetics but if not kept up through postgraduate education/practice application then knowledge diminishes. Aren't training programs required to include genetics? And also for CME's for RNs and MDs and other professional groups.</p>
<p>B. <u>Establishing and maintaining standards for testing and screening:</u> Need a formal mechanism to facilitate the analysis by a professional panel of all testing and screening currently in place to assure tests are appropriate, effective and accessible. The professional panel will require dedicated staff to assist in this work. Where to house this project?</p>	<p>Such a process is already in place.</p> <p>Suggest employing an MD/PhD student to do this.</p> <p>Suggest MSDH is place to do this.</p>
<p>C. <u>New information on genomics:</u> Annual review and updates of research findings. Such a process could be undertaken collaboratively among UMC, MSDH and representatives from professional associations. Information from analysis and review of new information transferred to training programs and to education programs for public and legislature. This group's work would require staff support.</p>	<p>Research leads to development of standards of care.</p> <p>Essential for on-going success: having accurate and updated clinical information for providers. Suggest getting staff will be an issue. A continuing education program could result from such review. These review results could be presented at annual professional meetings. Present results as clinical practice guideline/updates disseminate statewide.</p> <p>Ill defined goals: "research findings" -- too removed from clinical arena.</p>

Staff of MSDH Genetics Program then reviewed the Task Force comments and decided to use all five action/issue categories as the framework for the Genetics Services Plan—some categories were already underway within MSDH, others not yet begun. When new initiatives are developed, their integration will be guided by the Plan framework.

TASK FORCE SUMMARY STATEMENTS ON THE GAPS IDENTIFIED THROUGH THE NEEDS ASSESSMENT:

Issue #1: Enhanced information system for mother and child population: Data resources exist in various agencies - public and private. What additional data are needed and how do we integrate these for analysis and application? Existing Data Unit at MSDH requires additional dedicated staff to oversee this three-part effort: A team is needed that determines existing data resources, identifies gaps, specifies new resources that are needed, and develops a data integration process and analysis plan.

Support was expressed for enhanced information system but caution emphasized at the many barriers to its achievement. Establishing a super-data unit within the health department/Genetics Division was considered a priority with inclusion of epidemiological, biostatistical, economic, and geneticist resources. Management of such a unit would require a data manager and an interagency team for guidance and support in integrating across agencies. Barriers to these accomplishments include the software and hardware incompatibility within and across agencies, new HIPPA regulations. A protracted time line was predicted - 5-10 years due to the barriers. A complete baseline review was suggested to assess what is available prior to enhancements.

Issue # 2: Integrated and coordinated genetic services must be accessible throughout the state's public and private health systems. Maintenance of quality and adherence to standards, are essential components of these services. A dedicated structure and process needed to accomplish with sufficient staff for planning, implementation and maintenance of these services.

Support was expressed for integration and coordination of genetic services. Special emphasis made regarding the extension of pediatric genetic disorders into adulthood; planning for integration and transition into adulthood is the new challenge for clinicians. The need for national standards in clinical practice was stated but none are currently available. So quality assurance should be under the purview of an advisory group with record reviews, an expensive and labor-intensive process, an option for quality assurance. It was suggested that the compliance standards used for hospitals could include new standards for genetic services in the lab and the clinic. No support expressed for law enforcement through punitive measures; rather education and surveillance and reliance on consumer hotlines to monitor compliance.

Issue # 3: Family support services are found across multiple public and private entities; eligibility information about these must be integrated for enhanced consumer and provider access. Such an enhanced information system provides a first step to understanding current options for financial support. Widespread use will identify statewide limitations and suggest opportunities for expansion through legislative and private initiatives. This ambitious work plan requires dedicated staff with expertise and close work with advocacy groups and providers. Where would this work be implemented?

Unequivocal agreement was voiced that determination of financial eligibility is a time-consuming and cumbersome process that overwhelms providers and staff. The use of a web site was supported with consumers entering own eligibility information to receive relevant service options. Suggest that such a web site would be a joint effort of the Health Department and Department of Human Services. Overcoming transportation barriers through existing programs at Medicaid, HeadStart, Ryan White Program was discussed. Initiate a formal process to involve Medicaid, the Departments of Transportation, Education and Head Start to study availability now. Greater use of satellite clinics was also offered as an option to ease transportation barriers.

Issue #4: Facilitate development of legislative initiatives for genetic services with consumer and provider input and support. Process requires education of and dialogue among consumers, providers, and legislators, and understanding of current system of genetic services. How to implement process?

This was deemed the most challenging issue of all. Educating the public and legislature on the importance of genetics was noted to be very difficult as disease processes are rare. However, it is public awareness and activism that drives legislative actions. It was emphasized that vigilance must be exercised in counteracting simplified and false media expressions. Even if a strategic plan were to be employed - a process with an indefinite endpoint - how would we measure its benefits? Parent support groups should be a joint effort through the Health Department and the March of Dimes using the media to get public's attention.

Issue # 5: Provider training and education is a critical link to maintenance of standards in testing and patient care. Training provides opportunities for updating with new information and application to consumer services. New information also linked to public and legislator education programs. This work requires dedicated staff and support resources.

While several members voiced support for enhanced professional education some were skeptical about any one's ability to impact baccalaureate/professional curricula. Locating this effort within the university system was suggested for pre-service training and then integrating genetics into continuing education requirements for professional licensure renewals. Continuing education requirements were also cited as a critical focus for presenting new information on genomics to professionals on a regular basis. Caution was expressed that all education on genetics – basic information or new research findings -- must be presented with relevance to the practicing professional.

References

Dalaker, Joseph. *Poverty in the United States: 2000*. U.S. Department of Commerce, Economics and Statistics Administration, U.S. Census Bureau. Washington. September 2001. Internet on-line. <http://www.census.gov/prod/2001pubs/p60-214.pdf>. [21 February 2002]

Genetics Education Center, University of Kansas Medical Center. *Prevalence of Genetic Condition/Birth Defects: A Variety of References*. 2002. Internet on-line. <http://www.kumc.edu/gec/prof/prevalnc.html>. [29 January 2002].

Hebbeler, Kathleen, et al. *A First Look at the Characteristics of Children and Families Entering Early Intervention Services*. National Early Intervention Longitudinal Study. SRI International, September 27, 2001. Page 5. Internet on-line. <http://www.sri.con/neils/>. [21 February 2002]

Annie E. Casey Foundation. *KIDS COUNT Census Data Online*. Internet on-line. <http://www.aecf.org/cgi-bin/aecensus2.cgi?action=profileresults&area=26>. [27 February 2002]

Annie E. Casey Foundation. *KIDS COUNT The Right Start Online*. Internet on-line. <http://www.aecf.org/cgi-bin/rs2002/rightstart2002.cgi?action=profile&area=Mississippi>. [27 February 2002]

March of Dimes Foundation. *Perinatal Profiles: Statistics for Monitoring State Maternal and Infant Health, Mississippi Edition*. June 2001.

Mississippi State Department of Health. *Vital Statistics, Mississippi 2000*.

Mississippi State Department of Health. *Mississippi's Early Intervention Program, Annual Performance Report, 1999-2000*. 2001.

Social Security Administration, Office of Policy, Office of Research, Evaluation and Statistics. *Children Receiving SSI December 2000. Table 5. Number of children receiving federally administered SSI payments and average monthly amount, by region and state, December 2000*. Internet on-line. http://www.ssa.gov/statistics/children_recving_ssi/dec2000/chreport.pdf. [11 March 2002]

Social Security Administration, Office of Policy. *SSI Recipients by State and County, December 2000. Table 1. Number of persons receiving federally administered SSI payments and amount of payments, by program category, age receipt of OASDI, and state, December 2000. Table 2. Amount of federally administered SSI payments, by state, December 2000. Table 3. Number of persons receiving federally administered SSI payments and amount of payments, by program category, age, receipt of OASDI, and state and county, December 2000*. Internet on-line. http://www.ssa.gov/statistics/ssi_st_cty/2000/index.html. [11 March 2002]

U.S. Census Bureau. *Statistical Abstract of the United States: 2001*. No. 219. Educational Attainment by State: 1990 and 2000. Internet on-line. <http://www.census.gov/prod/2002pubs/01statab/educ.pdf>. [11 March 2002]

U.S. Census Bureau. *Table DP-1. Profile of General Demographic Characteristics for Mississippi: 2000*. Internet on-line.

http://factfinder.census.gov/servlet/QTTable?ds_name=DEC_2000_SF1U&geo_id=04000US28&gr_name=DEC_2000SF1_U_DP1. [19 February 2002]

U.S. Census Bureau. *QT-03. Profile of Selected Economic Characteristics: 2000*. American Fact Finder. Internet on-line.

http://factfinder.census.gov/servlet/QTTable?ds_name=ACS_C2SS_EST_G00&geo_id=04000US28&qtr_name=ACS_C2SS_EST_G00_QT03. [27 February 2002]

U.S. Census Bureau. *Quick Tables DP-4. Income and Poverty Status in 1989: 1990*. American Fact Finder. Internet on-line.

http://factfinder.census.gov/servlet/BasicFactsTable?_lang=en&_vt_name=DEC_1990_STF3_DP4&_geo_id=04000US28. [19 February 2002]

APPENDICES:

- A. The State Health Officer's Task Force on Genetic Services: Membership List and Meeting Agendas.**
- B. Table Appendix B-1: Distribution of Unduplicated Medicaid Recipients <21 Years of Age Receiving Genetic Services by County of Residence and ICD 9 Categories for 2000**
- C. Table Appendix C-1: Distribution of Medicaid Reimbursement Dollars for Genetic Services by County of Recipient Residence and ICD 9 Categories for Children <21, 2000**
- D. Surveys of Professionals and Training Programs/GenESES Genetic Education for the Southeastern States**
- E. A Report of the Consumer, Provider, and Administrator Surveys on Genetic Services in Mississippi**

**APPENDIX A: The State Health Officer's Task Force on Genetic Services:
Membership List and Meeting Agendas.**

The State Health Officer's Task Force on Genetic Services Membership List

Georg O. Bock, M.D.
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Department of Preventive Medicine

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American Academy of Pediatrics

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Mississippi Department of Finance and Administration

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Peggy O'Neill Hewlett, Ph.D, RN
Prof. And Assoc. Dean for Research
UMMC School of Nursing

Robin Haygood
Parent/Consumer Representative

Ex Officio Members of the Task Force

Jerry McClure
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Danny Bender
Director, Bureau of Child Health
Mississippi State Department of Health

Mike Gallarno
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Wanda Patterson
Perinatal High Risk Management (PHRM)
Bureau of Women's Health
Mississippi State Department of Health

Carolyn Green
Executive Director
March of Dimes, MS Chapter

**STATE HEALTH OFFICER'S GENETICS PLAN TASK FORCE
AGENDA FOR AUGUST 14, 2001 - Afternoon**

- | | |
|-----------------|--|
| 12:00 PM | Lunch |
| 12:45 PM | Genetic services in Mississippi
Jerry McClure, Director of Genetic Services, MSDH |
| 1:00 PM | Welcome to the Task Force
Dave Beck, Director
Office of Personal Health Services
for Dr. Ed Thompson, State Health Officer |
| 1:15 PM | The Genetics Planning Project:
Why it's needed, current and future activities.
Dr. Ruth Laufer, Project Coordinator/Consultant |
| 1:30 PM | Parent Panel Presentation: Telling the family's story - what it
means to need genetic services. Every day life with genetic
disorders and birth defects.
Alma Ellis, Project Co-Coordinator,
Institute for Disability Studies, USM |
| 2:30 PM | Task Force small group discussions: How parent stories
illustrate the six critical components of genetic services.
Problems and possible solutions.
Alma Ellis, Institute for Disability Studies, USM
Dr. Valerie DeCoux, Institute for Disability Studies, USM |
| 3:15 PM | Concluding Remarks
Dr. Ruth Laufer
Dr. Georg Bock
Jerry McClure |

**Genetics Plan Task Force
Agenda for May 28, 2002 Meeting**

10:00 AM	Welcome	Jerry McClure
10:15 AM	The State Genetics Plan Update	Dr. Ruth Laufer Alma Ellis
10:45 AM	Task Force Small Group Discussions	
11:45 AM	Concluding Remarks	Jerry McClure
12:00 PM	Lunch (provided)	

**APPENDIX B: Table Appendix B-1: Distribution of Unduplicated Medicaid Recipients
<21 Years of Age Receiving Genetic Services by County of Residence and
ICD 9 Categories for 2000**

Table B-11: Distribution of Unduplicated Medicaid Recipients < 21 Years of Age Receiving Genetic Services by County of Residence and ICD 9 Categories for 2000

Primary Diagnosis and ICD 9 Code for Services	Adams	Alcorn	Amite	Attala	Benton	Bolivar	Calhoun	Carroll	Chickasaw	Choctaw	Claiborne
Wilm's tumor, retinoblastoma, other congenital neoplasms (189-191)	1	-	-	-	-	1	-	-	-	1	-
Endocrine disorders (237-259)	38	27	21	11	25	61	13	9	21	11	18
Metabolic and immune disorders (270-275)	30	17	6	4	7	13	3	4	-	-	5
Metabolic and immune disorders (277-279)	28	17	9	12	4	16	8	1	11	12	5
Specified anemias, coagulation defects (282-284)	46	10	19	52	7	94	13	9	15	15	18
Specified anemias, coagulation defects (286)	-	-	-	-	-	-	-	-	-	-	-
Nervous system disorders (330-343)	15	7	6	5	5	15	4	4	3	7	6
Nervous system disorders (352 - 359)	5	5	-	1	2	10	1	3	4	2	4
Retinal disorders (362-363)	9	7	3	4	-	13	3	1	3	4	5
Blindness (369)	-	-	-	-	-	-	-	-	-	-	-
Hearing loss (389)	-	-	-	-	-	-	-	-	-	-	-
Cardiomyopathy and conduction disorders (Exclude 427.5 cardiac arrest) (425-427)	4	-	1	-	1	6	-	1	5	-	1
Dentofacial anomalies 524	-	-	-	-	-	1	-	-	-	-	-
Congenital anomalies (740-759)	145	86	33	74	19	145	40	19	58	34	32

Source: Division of Medicaid, Mississippi

Table B-1²: Distribution of Unduplicated Medicaid Recipients < 21 Years of Age Receiving Genetic Services by County of Residence and ICD 9 Categories for 2000											
Primary Diagnosis and ICD 9 Code for Services	Clarke	Clay	Coahoma	Copiah	Covington	Desoto	Forrest	Franklin	George	Greene	Grenada
Wilm's tumor, retinoblastoma, other congenital neoplasms (189-191)	-	1	2	1	-	-	3	1	2	-	1
Endocrine disorders (237-259)	9	21	40	31	25	19	81	13	14	10	19
Metabolic and immune disorders (270-275)	1	8	4	9	3	-	21	8	4	3	4
Metabolic and immune disorders (277-279)	11	11	15	27	6	11	35	6	11	6	7
Specified anemias, coagulation defects (282-284)	20	36	74	34	33	22	99	13	10	6	23
Specified anemias, coagulation defects (286)	-	-	-	-	-	-	-	-	-	-	-
Nervous system disorders (330-343)	6	7	18	20	7	14	34	1	5	2	7
Nervous system disorders (352 - 359)	3	4	3	6	-	8	5	4	-	1	3
Retinal disorders (362-363)	4	5	8	8	10	20	45	2	3	1	9
Blindness (369)	-	1	-	-	-	-	-	-	-	-	-
Hearing loss (389)	-	-	-	-	-	1	1	-	-	-	-
Cardiomyopathy and conduction disorders (Exclude 427.5 cardiac arrest) (425-427)	-	1	5	1	-	1	2	1	-	2	2
Dentofacial anomalies 524	-	-	-	-	-	-	-	-	-	-	-
Congenital anomalies (740-759)	42	73	109	100	71	138	235	33	49	29	54

Source: Division of Medicaid, Mississippi

Table B-1³: Distribution of Unduplicated Medicaid Recipients < 21 Years of Age Receiving Genetic Services by County of Residence and ICD 9 Categories for 2000

Primary Diagnosis and ICD 9 Code for Services	Hancock	Harrison	Hinds	Holmes	Humphreys	Issaquena	Itawamba	Jackson	Jasper	Jefferson	Jefferson Davis	Jones
Wilm's tumor, retinoblastoma, other congenital neoplasms (189-191)	-	4	15	-	1	-	-	3	-	1	-	-
Endocrine disorders (237-259)	42	261	154	36	19	1	11	61	14	7	17	58
Metabolic and immune disorders (270-275)	23	47	27	11	8	1	2	32	9	9	5	33
Metabolic and immune disorders (277-279)	8	79	198	31	20	-	3	18	7	3	9	33
Specified anemias, coagulation defects (282-284)	10	108	310	62	33	3	4	38	16	34	34	40
Specified anemias, coagulation defects (286)	-	1	-	-	-	-	-	-	-	-	-	-
Nervous system disorders (330-343)	7	59	111	14	8	-	7	37	14	1	7	29
Nervous system disorders (352 - 359)	3	10	14	9	1	2	1	6	2	1	1	8
Retinal disorders (362-363)	10	56	105	6	5	2	3	19	6	2	13	23
Blindness (369)	-	-	-	-	-	-	-	-	-	-	-	-
Hearing loss (389)	-	-	-	-	1	-	-	-	-	-	-	1
Cardiomyopathy and conduction disorders (Exclude 427.5 cardiac arrest) (425-427)	2	8	18	2	2	1	-	9	1	2	-	5
Dentofacial anomalies 524	-	-	-	-	-	-	-	-	-	-	-	-
Congenital anomalies (740-759)	103	544	769	149	48	6	44	324	47	22	49	235

Source: Division of Medicaid, Mississippi

Table B-1 4: Distribution of Unduplicated Medicaid Recipients < 21 Years of Age Receiving Genetic Services by County of Residence and ICD 9 Categories for 2000												
Primary Diagnosis and ICD 9 Code for Services	Kemper	Lafayette	Lamar	Lauderdale	Lawrence	Leake	Lee	Leflore	Lincoln	Lowndes	Madison	Marion
Wilm's tumor, retinoblastoma, other congenital neoplasms (189-191)	-	1	3	2	-	1	2	-	-	3	3	1
Endocrine disorders (237-259)	9	18	30	61	9	26	34	48	22	61	45	85
Metabolic and immune disorders (270-275)	-	3	7	7	6	6	9	37	7	8	11	5
Metabolic and immune disorders (277-279)	1	4	15	25	8	7	13	44	24	45	54	12
Specified anemias, coagulation defects (282-284)	10	31	21	39	10	20	37	72	16	83	86	47
Specified anemias, coagulation defects (286)	-	-	-	-	-	-	-	-	-	-	-	-
Nervous system disorders (330-343)	5	3	14	36	9	10	31	14	13	30	26	16
Nervous system disorders (352 - 359)	1	2	3	1	4	2	6	6	2	7	2	4
Retinal disorders (362-363)	3	7	18	26	3	3	25	10	11	18	14	15
Blindness (369)	-	-	-	-	-	-	-	-	-	-	-	-
Hearing loss (389)	-	-	-	-	-	-	3	1	-	1	-	1
Cardiomyopathy and conduction disorders (Exclude 427.5 cardiac arrest) (425-427)	-	1	2	8	1	2	7	5	-	3	2	2
Dentofacial anomalies (5240)	-	-	-	-	-	-	-	-	-	-	-	-
Congenital anomalies (740-759)	35	40	106	191	42	73	153	151	93	159	170	107

Source: Division of Medicaid, Mississippi

Table B-1⁵: Distribution of Unduplicated Medicaid Recipients < 21 Years of Age Receiving Genetic Services by County of Residence and ICD 9 Categories for 2000

Primary Diagnosis and ICD 9 Code for Services	Marshall	Monroe	Montgomery	Neshoba	Newton	Noxubee	Oktibbeha	Panola	Pearl River	Perry	Pike	Pontotoc	Prentiss
Wilm's tumor, retinoblastoma, other congenital neoplasms (189-191)	-	-	-	-	-	-	1	1	1	1	1	-	-
Endocrine disorders (237-259)	18	16	11	21	9	19	22	43	44	13	78	12	16
Metabolic and immune disorders (270-275)	5	4	1	7	7	11	6	10	20	-	3	3	3
Metabolic and immune disorders (277-279)	15	13	2	11	5	13	22	16	15	4	21	4	3
Specified anemias, coagulation defects (282-284)	25	18	10	24	12	15	36	46	18	32	69	5	7
Specified anemias, coagulation defects (286)	-	-	-	-	-	-	-	-	-	-	-	-	-
Nervous system disorders (330-343)	12	10	4	13	11	4	12	7	18	4	17	7	11
Nervous system disorders (352 - 359)	2	1	2	1	1	5	2	1	1	-	3	-	-
Retinal disorders (362-363)	9	8	2	11	4	4	4	15	19	5	18	2	1
Blindness (369)	-	-	-	-	-	-	-	-	-	-	-	-	-
Hearing loss (389)	-	-	-	-	-	-	-	-	-	1	-	1	1
Cardiomyopathy and conduction disorders (Exclude 427.5 cardiac arrest) (425-427)	2	6	1	3	1	-	2	1	5	2	2	2	1
Dentofacial anomalies (5240)	-	-	-	-	-	-	-	-	-	-	-	-	-
Congenital anomalies (740-759)	64	78	35	107	67	48	107	109	142	45	129	46	61

Source: Division of Medicaid, Mississippi

Table B-1⁶: Distribution of Unduplicated Medicaid Recipients < 21 Years of Age Receiving Genetic Services by County of Residence and ICD 9 Categories for 2000													
Primary Diagnosis and ICD 9 Code for Services	Quitman	Rankin	Scott	Sharkey	Simpson	Smith	Stone	Sunflower	Tallahatchie	Tate	Tippah	Tishomingo	Tunica
Wilm's tumor, retinoblastoma, other congenital neoplasms (189-191)	-	-	1	-	-	-	1	1	-	-	-	-	-
Endocrine disorders (237-259)	40	48	22	19	47	21	24	32	19	19	18	10	8
Metabolic and immune disorders (270-275)	6	3	15	3	3	5	4	14	3	4	4	2	3
Metabolic and immune disorders (277-279)	5	27	11	8	11	13	10	25	25	11	5	4	3
Specified anemias, coagulation defects (282-284)	27	30	32	19	25	17	10	47	31	13	6	1	13
Specified anemias, coagulation defects (286)	-	-	-	-	-	-	-	-	-	-	-	-	-
Nervous system disorders (330-343)	5	37	17	-	15	3	9	13	6	3	7	3	4
Nervous system disorders (352 - 359)	1	8	1	1	3	2	2	4	2	2	2	1	-
Retinal disorders (362-363)	3	12	12	-	15	6	8	17	4	7	5	4	1
Blindness (369)	-	-	-	-	-	-	-	-	-	-	-	-	-
Hearing loss (389)	-	-	-	-	-	-	-	-	-	-	-	-	-
Cardiomyopathy and conduction disorders (Exclude 427.5 cardiac arrest) (425-427)	1	4	3	-	3	1	-	2	1	1	2	2	-
Dentofacial anomalies (5240)	1	-	-	-	-	-	-	-	-	-	-	-	-
Congenital anomalies (740-759)	38	219	116	33	83	50	57	108	55	57	51	53	28

Source: Division of Medicaid, Mississippi

Table B-17: Distribution of Unduplicated Medicaid Recipients < 21 Years of Age Receiving Genetic Services by County of Residence and ICD 9 Categories for 2000											
Primary Diagnosis and ICD 9 Code for Services	Union	Walthall	Warren	Washington	Wayne	Webster	Wilkinson	Winston	Yalobusha	Yazoo	State
Wilm's tumor, retinoblastoma, other congenital neoplasms (189-191)	1	-	1	2	-	-	1	-	-	1	65
Endocrine disorders (237-259)	11	293	31	71	18	6	12	14	12	37	2,830
Metabolic and immune disorders (270-275)	2	4	10	13	3	1	3	5	4	6	665
Metabolic and immune disorders (277-279)	5	6	27	52	16	5	3	6	4	19	1,369
Specified anemias, coagulation defects (282-284)	11	11	37	168	21	3	18	25	13	38	2,742
Specified anemias, coagulation defects (286)	-	-	-	-	-	-	-	-	-	-	1
Nervous system disorders (330-343)	3	8	23	38	7	6	7	7	-	6	1,041
Nervous system disorders (352 - 359)	1	1	5	9	2	-	1	1	1	3	245
Retinal disorders (362-363)	3	6	23	28	6	3	3	6	2	16	860
Blindness (369)	-	-	-	-	-	-	-	-	-	-	1
Hearing loss (389)	-	-	-	1	-	-	-	-	-	-	14
Cardiomyopathy and conduction disorders (Exclude 427.5 cardiac arrest) (425-427)	2	2	6	6	1	-	1	-	-	4	183
Dentofacial anomalies (5240)	-	-	-	-	-	-	-	-	-	-	2
Congenital anomalies (740-759)	47	57	170	274	57	30	41	66	35	113	8,098

Source: Division of Medicaid, Mississippi

APPENDIX C: Table Appendix C-1: Distribution of Medicaid Reimbursement Dollars for Genetic Services by County of Recipient Residence and ICD 9 Categories for Children <21, 2000

Table C-11: Distribution of Medicaid Reimbursement Dollars for Genetic Services by County of Recipient Residence and ICD 9 Categories for Children <21, 2000

Primary Diagnosis and ICD 9 Code for Services	Adams	Alcorn	Amite	Attala	Benton	Bolivar	Calhoun	Carroll	Chickasaw	Choctaw	Claiborne
Wilm's tumor, retinoblastoma, other congenital neoplasms (189-191)	37	-	-	-	-	70	-	-	-	231	-
Endocrine disorders (237-259)	6,508	2,859	6,274	3,012	2,735	22,999	8,112	6,798	13,263	6,613	6,872
Metabolic and immune disorders (270-275)	1,744	1,810	956	159	554	587	702	477	-	-	299
Metabolic and immune disorders (277-279)	1,782	19,245	6,398	636	170	2,593	21,360	106	622	7,849	191
Specified anemias, coagulation defects (282-284)	95,233	314	20,915	13,435	305	93,538	5,079	5,038	6,076	29,580	32,696
Specified anemias, coagulation defects (286)	-	-	-	-	-	-	-	-	-	-	-
Nervous system disorders (330-343)	7,095	726	223	6,693	2,044	8,435	3,303	812	4,177	982	4,314
Nervous system disorders (352 - 359)	1,771	4,193	-	33	808	1005	266	801	390	241	1,022
Retinal disorders (362-363)	698	1,084	529	1,073	-	1469	815	31	235	4	1,630
Blindness (369)	-	-	-	-	-	-	-	-	-	-	-
Hearing loss (389)	-	-	-	-	-	-	-	-	-	-	-
Cardiomyopathy and conduction disorders (Exclude 427.5 cardiac arrest) (425-427)	1703	-	56	-	752	21,940	-	2,078	1,653	-	161
Dentofacial anomalies 524	-	-	-	-	-	449	-	-	-	-	-
Congenital anomalies (740-759)	139,051	55,359	73,410	170,267	9,087	237,951	27,084	17,491	87,405	28,657	44,564

Source: Division of Medicaid, Mississippi

Table C-12: Distribution of Medicaid Reimbursement Dollars for Genetic Services by County of Recipient Residence and ICD 9 Categories for Children <21, 2000											
Primary Diagnosis and ICD 9 Code for Services	Clarke	Clay	Coahoma	Copiah	Covington	Desoto	Forrest	Franklin	George	Greene	Grenada
Wilm's tu mor, retinoblastoma, other congenital neoplasams (189-191)	-	58	20,910	1,124	-	-	555	704	5,730	-	-
Endocrine disorders (237-259)	3,975	2,595	18,454	13,190	39,018	3,660	33,111	2,231	7,725	1,869	9,977
Metabolic and immune disorders (270-275)	109	6,235	151	468	188	-	2,642	388	820	240	134
Metabolic and immune disorders (277-279)	1,379	1,275	5,116	6,447	352	1,374	36,388	702	801	230	1,281
Specified anemias, coagulation defects (282-284)	35,471	15,418	86,429	59,660	10,944	8,809	227,494	14,982	562	25,727	10,862
Specified anemias, coagulation defects (286)	-	-	-	-	-	-	-	-	-	-	-
Nervous system disorders (330-343)	6,197	5,210	13,063	68,344	3,169	9,125	12,142	5,159	3,146	765	708
Nervous system disorders (352 - 359)	18,779	980	227	314	-	1,170	1,098	252	-	225	440
Retinal disorders (362-363)	458	1,642	1,764	901	1,332	3,314	7,221	107	482	203	2,155
Blindness (369)	-	163	-	-	-	-	-	-	-	-	-
Hearing loss (389)	-	-	-	-	-	31	90	-	-	-	-
Cardiomyopathy and conduction disorders (Exclude 427.5 cardiac arrest) (425-427)	-	1,508	28,138	133	-	281	80	100	-	94	165
Dentofacial anomalies 524	-	-	-	-	-	-	-	-	-	-	-
Congenital anomalies (740-759)	37,556	52,030	211,376	56,793	141,203	106,392	246,318	23,274	65,426	60,691	341,271

Source: Division of Medicaid, Mississippi Note: Providers receiving this reimbursement may or may not be located in the child's county of residence.

Table C-1³: Distribution of Medicaid Reimbursement Dollars for Genetic Services by County of Recipient Residence and ICD 9 Categories for Children <21, 2000												
Primary Diagnosis and ICD 9 Code for Services	Hancock	Harrison	Hinds	Holmes	Humphreys	Issaquena	Itawamba	Jackson	Jasper	Jefferson	Jefferson Davis	Jones
Wilm's tumor, retinoblastoma, other congenital neoplasms (189-191)	-	1,804	11,791	-	118	-	-	7,732	-	113	-	-
Endocrine disorders (237-259)	38,356	102,762	261,374	30,208	10,163	44	6,620	18,256	6,342	7,890	11,042	40,644
Metabolic and immune disorders (270-275)	1,066	9,375	16,168	609	347	108	193	27,309	633	433	234	25,273
Metabolic and immune disorders (277-279)	741	206,067	36,322	2,181	1,160	-	705	5,236	1,649	405	602	4,489
Specified anemias, coagulation defects (282-284)	456	226,993	609,195	18,838	14,149	468	82	63,009	889	34	9,760	20,018
Specified anemias, coagulation defects (286)	-	12	-	-	-	-	-	-	-	-	-	-
Nervous system disorders (330-343)	4,758	87,102	78,023	1,568	1,458	-	7,968	18,834	16,130	136	1,628	34,464
Nervous system disorders (352 - 359)	133	716	3,556	703	60	133	914	707	350	684	33	6,096
Retinal disorders (362-363)	2,790	15,128	22,282	751	6,308	208	883	1,722	809	1,233	28,835	6,054
Blindness (369)	-	-	-	-	-	-	-	-	-	-	-	-
Hearing loss (389)	-	-	-	-	69	-	-	-	-	-	-	122
Cardiomyopathy and conduction disorders (Exclude 427.5 cardiac arrest) (425-427)	396	1,857	11,871	567	570	804	-	1,295	2,865	8,116	-	8,306
Dentofacial anomalies 524	-	-	-	-	-	-	-	-	-	-	-	-
Congenital anomalies (740-759)	86,619	722,564	1,199,092	108,957	48,305	1,140	30,217	283,203	47,556	23,957	52,650	335,052

Source: Division of Medicaid, Mississippi

Table C-14: Distribution of Medicaid Reimbursement Dollars for Genetic Services by County of Recipient Residence and ICD 9 Categories for Children <21, 2000												
Primary Diagnosis and ICD 9 Code for Services	Kemper	Lafayette	Lamar	Lauderdale	Lawrence	Leake	Lee	Leflore	Lincoln	Lowndes	Madison	Marion
Wilm's tumor, retinoblastoma, other congenital neoplasms (189-191)	-	243	189	248	-	466	534	-	-	20,268	3,634	26
Endocrine disorders (237-259)	2,790	20,730	21,206	34,509	6,012	4,947	11,324	22,397	6,899	33,263	34,482	24,707
Metabolic and immune disorders (270-275)	-	129	2,523	492	1,693	306	384	4,024	727	307	847	456
Metabolic and immune disorders (277-279)	310	1,442	7,717	18,555	659	966	7,417	4,812	17,448	12,776	5,272	1,018
Specified anemias, coagulation defects (282-284)	1,419	82,177	35,440	56,812	2,644	19,366	26,222	66,387	10,093	47,714	74,706	20,399
Specified anemias, coagulation defects (286)	-	-	-	-	-	-	-	-	-	-	-	-
Nervous system disorders (330-343)	791	5,017	6,722	19,574	2,515	7,171	86,090	5,176	6,501	40,322	62,192	78,058
Nervous system disorders (352 - 359)	534	96	1,244	16	3,848	29,052	3,886	2,255	52	2,118	185	3,027
Retinal disorders (362-363)	808	2,098	1,367	21,353	562	324	4,992	1,399	1,496	4,383	1,776	2,655
Blindness (369)	-	-	-	-	-	-	-	-	-	-	-	-
Hearing loss (389)	-	-	-	-	-	-	104	134	-	63	-	141
Cardiomyopathy and conduction disorders (Exclude 427.5 cardiac arrest) (425-427)	-	15	885	16,529	18	26,470	2,307	1,118	-	2,708	144	84
Dentofacial anomalies (524)	-	-	-	-	-	-	-	-	-	-	-	-
Congenital anomalies (740-759)	44,854	273,506	76,347	221,751	56,209	97,935	191,833	178,264	56,401	281,123	147,692	110,139

Source: Division of Medicaid, Mississippi

Table C-1⁵: Distribution of Medicaid Reimbursement Dollars for Genetic Services by County of Recipient Residence and ICD 9 Categories for Children <21, 2000													
Primary Diagnosis and ICD 9 Code for Services	Marshall	Monroe	Montgomery	Neshoba	Newton	Noxubee	Oktibbeha	Panola	Pearl River	Perry	Pike	Pontotoc	Prentiss
Wilm's tumor, retinoblastoma, other congenital neoplasms (189-191)	-	-	-	-	-	-	118	63	156	159	647	-	-
Endocrine disorders (237-259)	8,685	11,956	17,260	20,444	18,507	12,540	6,044	9,187	7,114	5,321	22,740	4,370	9,668
Metabolic and immune disorders (270-275)	314	152	44	4,268	587	448	701	3,473	1,251	-	147	159	143
Metabolic and immune disorders (277-279)	1,209	9,973	1,691	3,211	1,583	446	1,617	2,191	18,881	157	24,247	21,354	192
Specified anemias, coagulation defects (282-284)	15,715	4,506	13,924	3,150	12,117	49,688	21,168	60,794	15,418	4,122	40,639	13,570	413
Specified anemias, coagulation defects (286)	-	-	-	-	-	-	-	-	-	-	-	-	-
Nervous system disorders (330-343)	8,107	11,005	1,084	5,339	14,100	1,026	6,506	2,603	114,904	810	9,232	1,490	1,641
Nervous system disorders (352 - 359)	298	449	910	267	172	5,820	96	47	4,478	-	2,648	-	-
Retinal disorders (362-363)	1,739	1,487	895	2,101	352	1,409	659	2,698	2,505	1,705	6,188	109	198
Blindness (369)	-	-	-	-	-	-	-	-	-	-	-	-	-
Hearing loss (389)	-	-	-	-	-	-	-	-	-	79	-	49	33
Cardiomyopathy and conduction disorders (Exclude 427.5 cardiac arrest) (425-427)	638	1,033	62	595	910	-	1,208	577	5,481	128	894	784	434
Dentofacial anomalies (524)	-	-	-	-	-	-	-	-	-	-	-	-	-
Congenital anomalies (740-759)	131,748	136,016	36,334	132,042	80,000	197,700	130,796	213,783	103,754	39,044	134,108	26,929	379,770

Source: Division of Medicaid, Mississippi

Table C-1⁶: Distribution of Medicaid Reimbursement Dollars for Genetic Services by County of Recipient Residence and ICD 9 Categories for Children <21, 2000

Primary Diagnosis and ICD 9 Code for Services	Quitman	Rankin	Scott	Sharkey	Simpson	Smith	Stone	Sunflower	Tallahatchie	Tate	Tippah	Tishomingo	Tunica
Wilm's tumor, retinoblastoma, other congenital neoplasms (189-191)	-	-	883	-	-	-	16,266	347	-	-	-	-	-
Endocrine disorders (237-259)	2,765	12,987	21,029	4,287	15,469	7,050	5,374	15,559	4,070	12,177	7,324	4,661	1,120
Metabolic and immune disorders (270-275)	259	213	1,908	199	150	13,274	212	1,015	493	484	176	58	288
Metabolic and immune disorders (277-279)	484	44,491	973	488	4,847	722	24,153	1,416	2,087	20,317	1,100	574	203
Specified anemias, coagulation defects (282-284)	49,442	37,151	41,358	5,456	15,492	8,081	7,763	58,187	49,840	13,439	114	24	678
Specified anemias, coagulation defects (286)	-	-	-	-	-	-	-	-	-	-	-	-	-
Nervous system disorders (330-343)	470	20,284	5,224	-	6,313	863	8,733	5,168	1,189	608	5,066	979	4,195
Nervous system disorders (352 - 359)	0	2,394	52	33	478	65	122	10,747	196	86	353	13	-
Retinal disorders (362-363)	373	2,079	1,686	-	1,533	382	852	3,332	520	2,653	2,902	644	682
Blindness (369)	-	-	-	-	-	-	-	-	-	-	-	-	-
Hearing loss (389)	-	-	-	-	-	-	-	-	-	-	-	-	-
Cardiomyopathy and conduction disorders (Exclude 427.5 cardiac arrest) (425-427)	56	103,318	400	-	138,855	6,032	-	10,412	446	33	236	835	-
Dentofacial anomalies (524)	100	-	-	-	-	-	-	-	-	-	-	-	-
Congenital anomalies (740-759)	47,853	194,897	69,372	23,788	55,335	51,588	125,178	127,293	52,824	104,251	132,664	163,548	77,923

Source: Division of Medicaid, Mississippi.

Table C-17: Distribution of Medicaid Reimbursement Dollars for Genetic Services by County of Recipient Residence and ICD 9 Categories for Children <21, 2000											
Primary Diagnosis and ICD 9 Code for Services	Union	Walthall	Warren	Washington	Wayne	Webster	Wilkinson	Winston	Yalobusha	Yazoo	State
Wilm's tumor, retinoblastoma, other congenital neoplasms (189-191)	225	-	1,197	3,482	-	-	142	-	-	53	100,388
Endocrine disorders (237-259)	8,539	26,265	12,575	40,423	6,053	1,235	3,376	14,393	2,223	19,379	1,384,517
Metabolic and immune disorders (270-275)	77	4,985	658	718	118	98	182	3,371	292	364	153,647
Metabolic and immune disorders (277-279)	341	471	3,160	12,834	1,574	1,160	347	2,097	575	1,482	699,306
Specified anemias, coagulation defects (282-284)	10,672	22,622	50,270	310,314	15,242	7,968	21,537	23,968	4,931	102,156	3,365,628
Specified anemias, coagulation defects (286)	-	-	-	-	-	-	-	-	-	-	13
Nervous system disorders (330-343)	666	4,070	22,858	16,771	2,400	12,418	3,917	4,111	-	6,605	1,057,462
Nervous system disorders (352 - 359)	7	801	585	5,136	611	-	184	84	4,897	1,054	137,637
Retinal disorders (362-363)	785	703	3,793	8,236	1,537	205	348	711	277	2,194	216,378
Blindness (369)	-	-	-	-	-	-	-	-	-	-	164
Hearing loss (389)	-	-	-	50	-	-	-	-	-	-	971
Cardiomyopathy and conduction disorders (Exclude 427.5 cardiac arrest) (425-427)	145	3,643	7,181	6,501	12,983	-	423	-	-	2,534	452,571
Dentofacial anomalies (524)	-	-	-	-	-	-	-	-	-	-	549
Congenital anomalies (740-759)	36,325	62,359	180,488	318,650	63,511	33,394	32,302	48,952	62,943	103,546	21,868,878

Source: Division of Medicaid, Mississippi.

APPENDIX D: Surveys of Professionals and Training Programs/GenESES Genetic Education for the Southeastern States.

For a copy of this report, contact the Mississippi State Department of Health's Genetic Services Department at (601) 576-7619, or write to:

*Mississippi State Department of Health
Genetic Services
Post Office Box 1700
Jackson, MS 39215-1700*

**APPENDIX E: A Report of the Consumer, Provider, and Administrator Surveys on
Genetic Services in Mississippi**

A Summary of the Consumer, Provider, and Administrator Surveys on Genetic Services in Mississippi

February 13, 2002

Prepared by



The Institute for Disability Studies
The University of Southern Mississippi

Bodoni, 90%

Executive Summary

Three surveys were developed for the Genetics Services Planning Project of the Genetics Division of the Mississippi Department of Health to determine perceptions regarding genetic services as expressed by consumers, providers, and administrators.

A. Consumer Survey

A total of 625 surveys were mailed to parents of children with disabilities and 116 were returned—an 18.6 percent rate of return. The children of these respondents were distributed as follows for age, sex, and race:

Table 1: Age of Children of Respondents

Age Group	Percentage
0-3 years of age	36%
4-12 years of age	28%
13-21 years of age	13%
>21 years of age	9%
Total	100%

Table 2: Gender of Children of Respondents

Gender	Percentage
Male	58%
Female	36%
No Response	6%
Total	100%

Table 3: Race of Children of Respondents

Race	Percentage
White	44%
Non White	50%
No Response	6%
Total	100%

There were 14 possible problems listed on the survey that may be of significance to parents in caring for their children. These were ranked by respondents in order of importance with the following three ranking the highest:

22 percent noted it was *Not clear what financial coverage is available to us*,

19.3 percent noted *There are not specialized doctors close by so we have to travel far for some appointments*, and,

15.6 percent noted they *Can't find child care for my child with disabilities*.

Three other problem issues ranking highly with over 10 percent of respondents include the following:

We have not received information on parent support groups near where we live by 12.8 percent,

We have problems getting transportation for our children's appointments by 11 percent, and,

Because of transportation problems I sometimes have a hard time keeping appointments by 10.1 percent.

(Note that parents listed several issues with a “1” for the most critical or a “2” as the next most critical, etc., hence these percentages do not total 100 percent).

It can be summarized then that the following issues are important to parents of children who require genetic services:

1. understanding availability financial coverage
2. local availability of specialized physicians
3. child care
4. access to parent support groups
5. transportation

The results also showed that of the above listed issues, transportation and access to information, were more frequently mentioned as problems—over 50 percent more frequently—for black parents. Differences in perceptions by race regarding transportation and access to information are not surprising given the disparity in socioeconomic status between whites and blacks in Mississippi. Because respondents were not asked questions regarding socioeconomic status their answers cannot be definitively linked to this variable.

Geographic location also differentiated parents: those living in the southern portion of the state

cited transportation and understanding financial coverage 50 percent more frequently as problem issues than parents living in the central and northern regions of the state. These differences are explained by the greater accessibility in central Mississippi to the state's tertiary care center at University Medical Center. In the northern portion of the state access to tertiary care is found in Memphis, Tennessee, at LeBonheur Children's Medical Center and in Tupelo, Mississippi, at the North Mississippi Medical Center. Access to tertiary care in the southern portion of the state is more limited.

Positive consumer opinions included the following:

Genetics services have been a big help. When we call them they respond quickly.

Genetic screening of our child alleviated some of the concern that her condition was hereditary. Although her condition is genetic, it is a random occurrence condition.

At birth, genetic services were very helpful in explaining our diagnosis of Down syndrome.

B. Provider Survey

A total of 855 surveys were mailed to seven groups of providers working in the Mississippi Department of Health, University Medical Center, and community health centers around the state. Other providers included members of the Mississippi Perinatal Association and the Mississippi Chapter of the American Academy of Pediatrics. A total of 208 surveys were returned—a 24 percent return rate, by providers in 71 of 82 counties. All providers responded that they saw patients with birth defects and genetic disorders. These providers were distributed as follows by type of occupation:

<u>Table 4: Occupations of Providers Responding</u>	
<u>Occupation</u>	<u>Percentage Among Respondents</u>
Physicians	52%
Nurses	30%
Early Intervention Specialists	8%
Nurse Practitioners	3%
Social Workers	3%
Other	4%
Total	100%

Of 16 issues listed as important in caring for patients with genetic diagnoses, the following ranked in the top three by providers:

Not having specialized doctors available to refer patients close to their homes by 27.4 percent,

Overall management of patient is not coordinated among providers so there are duplications/gaps by 20.2 percent, and,

Limited availability of training programs to keep my skills up to date by 14.4 percent.

An additional six issues were rated as important by over 10 percent of respondents:

Other providers are not aware of nor do they understand what services we can provide (13.9 percent),

*Appointment keeping is a problem (13 percent),
Do not have a list of support groups available for referral of parents in our area (12.5 percent),*

Not enough skilled professionals (12.5 percent),

No transportation for our patients to get here (12.5 percent), and

Incomplete information available on patients referred to me by other providers (11.1 percent).

(Note that providers ranked several issues with a “1” for the most critical or a “2” as the next most critical, etc., hence these percentages do not total 100 percent.)

It can be summarized then, that responding providers of genetic services have the following major issues in caring for children with genetic conditions and disabilities:

1. insufficient skilled professionals for referrals
2. uncoordinated care management and information regarding patient care
3. lack of training programs to maintain skills
4. lack of information for providers regarding service availability and parent support groups
5. transportation for patients

Differences in responses were observed physicians, nurses and other provider types. Nurses chose 12 issues more frequently—some 50 percent more frequently—than physicians and other providers as their most important problem: patient transportation, duplication in patient management, incomplete patient information, no specialized doctors close to patient’s home, too many forms, lack of affordable child care, difficult system of care, limited training available, problem keeping appointment, other providers not aware of services, long wait for follow-up appointments, and no list of local support groups. This finding is not unexpected given the typical role of the nurse in managing and coordinating patient care and the greater ease of

patients in communicating with nurses rather than doctors. Nurses are therefore more aware of patient service problems than doctors.

Differences in responses were also noted by geographic location of the provider. Service coordination and availability of specialized doctors were two issues mentioned most frequently as problems for the southern portion of the state. As noted earlier these observations are related to the lack of accessible tertiary care specialists in southern Mississippi and the presence of a tertiary medical center in central Mississippi and limited referral access in northern Mississippi in Tupelo and in Memphis, Tennessee.

Open ended comments included general complaints about the lack of resources, lack of education, and need for follow-up information on newborn genetic screening for primary care providers. Other providers indicated their search for and implementation of priorities and programs that can work for people with genetic disorders and their families. Specific mention was made of transportation assistance, coordination of services, resources for referrals, and education and training.

C. Administrator Survey

A total of 89 surveys were mailed to program administrators in the Mississippi Department of Health, University Medical Center, community health centers around the state, and the Division of Medicaid. Of these, 41 were returned—a 46 percent rate of return. Administrators from programs in 36 counties and 5 different Health Department districts responded.

Of the 16 issues listed by administrators as important in caring for patients with genetic diagnoses, the top three included:

Transportation to our location is a problem for our patients by 47.5 percent,

Don't have available enough skilled professionals to staff program by 30 percent, and,

Not having specialized doctors available for referral of our patients close to their homes by 27.5 percent.

It is noteworthy that many more issues were ranked highly as problems for administrators than noted in responses of parents or providers. Responding administrators have taken the concerns of the patients and the providers into consideration in their responses. A total of 10 more issues were viewed by over 10 percent of respondents as important in addition to the top three:

Incomplete information available on patients referred to our program from other providers (22.5 percent),

Appointment keeping is a problem for our program (22.5 percent),

Do not have a list of support groups available for referral of parents (20 percent),

Overall management of patients services is not coordinated among providers (17.5 percent),

Limited availability of training programs to keep our staff skills up to date (17.5 percent),
Other providers not aware of nor do they understand our services (17.5 percent),
Reimbursement rates insufficient for our services (12.5 percent),
Lack of affordable childcare for patient's children (12.5 percent),
Availability of financial coverage for our patients not clear" (10 percent), and
My office staff or I are required to fill out too many forms (10 percent).

Administrators' list of problem issues can be summarized as follows:

1. transportation for patients
2. availability of skilled professionals within the program and for local community referrals (This includes training program availability.)
3. patient care management issues: insufficient information from other providers, excessive paperwork
4. financial coverage: insufficient reimbursement and information regarding financial assistance for patients
5. affordable child care for families

Analysis of administrators responses by geographic region demonstrated once again that issues that related to services to clients—the availability of skilled professionals, transportation, and support group information—were of greater concern (greater by 50 percent) away from the central region of the state where there is greater access to tertiary care.

Survey Summary

A comparison of issues ranked most problematic by consumers, providers, and administrators (Table 5) demonstrates that on the whole there is congruency in their choices with only a few unique issues chosen by each group. Availability of specialized physicians in areas of the state that are far away from tertiary care centers consistently appears as a concern for consumers and administrators (as “2,” next to the most critical) and for providers (as “1,” the most critical). Management issues (availability of information on patients, excessive paperwork) appear on the provider list (“2”) and the administrator list (“3”). Note that consumers ranked a related issue—their poor understanding of financial coverage—as the number one problem. Transportation is last on the list for consumers and providers but first for administrators. Financial coverage issues (including process complexity, and insufficient reimbursement) also appear first for consumers and fourth for administrators. Information and availability of parent support groups is another major issue of concern that is mentioned in open ended answers and is ranked highly by consumers and providers.

Table 5: Comparison of Issues Ranked Most Important by Consumers, Providers, and Administrators		
Consumer List	Provider List	Administrator List
Understanding financial coverage	Insufficient skilled professionals	Transportation for patients
Local availability of specialized physicians	Uncoordinated management and information regarding patient care	Availability of skilled professionals within the program and for local community referrals (and this would include training program availability)
Child care	Lack of training programs to maintain skills	Patient care management issues: insufficient information from other providers, excessive paperwork
Access to parent support groups	Lack of information for providers regard service availability and parent support groups	Financial coverage: insufficient reimbursement and information regarding financial assistance for patients
Transportation	Transportation for patients	Affordable child care for families

Three separate surveys were created for the Genetics Planning Project of the Genetics Division of the Mississippi Department of Health to determine the needs and perceptions regarding genetics services expressed by consumers, providers, and administrators.

The Consumer Survey

The one-page Survey on Genetic Services in Mississippi (See Appendix A.) was sent to a total of 625 parents from three different groups of parents of children with disabilities. A total of 252 surveys were mailed to members of the Institute for Disability Studies' Project VISSIONS (Visualizing an Integrated System of Supports: Innovative Opportunities and New Strategies) Community Assessment and Planning Team list on June 5. On June 13, another 294 surveys were mailed to the parents of a random sampling of children ages birth to three years being served by the Department of Health's First Steps Early Intervention Program. On July 2, a final 79 surveys were mailed to parents of the children being served by the Department of Health's Sickle Cell Program. A total of 116 of the parent surveys were returned. Of these, 109 were complete and were tabulated.

Parent Group Type	Number Mailed Out	Number Returned	Percentage Returned
Project VISSIONS	252	61	20.7%
First Steps	294	38	12.9%
Sickle Cell	79	17	21.5%
Total	625	116	18.6%

In the first section of the survey, parents were asked to check any problems of the 14 listed they or members of their family had encountered in seeking genetic services for their children. Parents were also asked in this section to enter numbers indicating with a "1" the most critical problem, "2" the next, etc. Respondents were to write "NA" if the issue was not a problem for them.

This section seemed confusing to parents. Some answered correctly using the numbers 1 through 14 to rank their answers, while others answered with multiple 1s, 2s, and 3s with several items being deemed as "most critical, the next most critical, or the next, etc." by an individual respondent. To be able to use as many of the returned surveys as possible, the ranking tabulation analysis was included for all the answered surveys.

The top three problems considered most important of all the problems listed in the first section were, in order:

Problem 4 - *Not clear what financial coverage is available to us* with 22 percent of the parents responding,

Problem 7 - *There are not specialized doctors close by so we have to travel far for some appointments* with 19.3 percent of the parents responding, and

Problem 13 - *Can't find child care for my child with disabilities* with 15.6 percent of the parents responding.

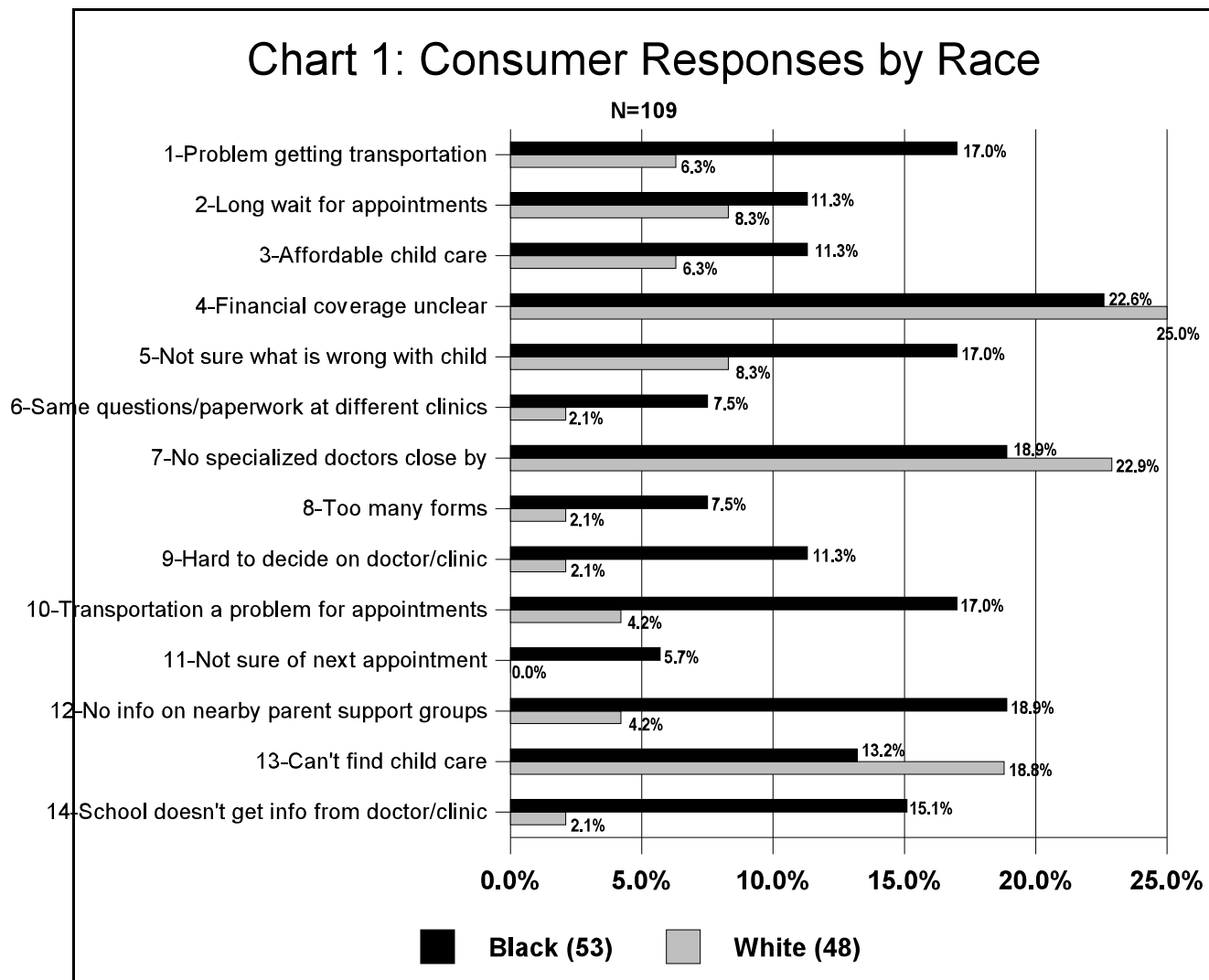
The following table lists the problems 1 through 14 as shown on the questionnaire and gives the percentage of parents who ranked the problems as their first, second, or third most critical issue. This percentage (%NA) is also shown in the table for problem. This records the percentage of parents answering that an issue was “not a problem” or “did not apply” to their family.

Table 7: Percentage of Parents Ranking Problems as Most Critical Issue for Their Children				
Problem	%Ranked 1st	%Ranked 2nd	%Ranked 3rd	% NA
1. We have problems getting transportation for our children's appointments.	11	1.8	2.8	73.4
2. We have to wait a long time to get an appointment for our children.	9.2	6.4	.9	73.4
3. There is a problem finding affordable child care for our children when we have appointments.	5.5	4.6	4.6	73.4
4. Not clear what financial coverage is available to us.	22	11	7.3	43.1
5. Not sure what is wrong with my child and how it happened	12.8	3.7	3.7	67
6. We sometimes get the same questions and paperwork at different clinics or doctor's offices.	4.6	8.3	4.6	66.1
7. There are not specialized doctors close by so we have to travel far for some appointments.	19.3	12.8	4.6	45.9
8. We have to fill out so many forms each time we go to the clinic.	5.5	7.3	4.6	67
9. It is hard to figure out which doctor or clinic to go to for our child's care.	6.4	6.4	6.4	67.9
10. Because of my transportation problems I sometimes have a hard time keeping appointments.	10.1	5.5	4.6	72.5
11. Not sure when we have to go to the doctor again.	2.8	.9	0	92.7
12. We have not receive information on parent support groups near where we live.	12.8	9.2	9.2	47.7
13. Can't find child care for my child with disabilities.	15.6	6.4	4.6	63.3
14. Our child's school doesn't get information from our doctor/clinic.	8.3	1.8	2.8	73.4
<i>Totals for rows do not add up to 100% because of multiple responses for each problem.</i>				

The respondents' answers to the 14 issues in this section of the survey were also analyzed by the respondents' race and the regions of the state in which they live to see if there were perhaps any differences according to these variables.

The following bar chart (Chart 1) shows respondents' answers by race using the percentage who

ranked the issue as a most critical concern. There was considerable difference between the rankings given by respondents of different races on eight of the 14 issues. Black respondents were more than twice as likely as white respondents to consider problems 1, 5, 6, 8, 9, 10, 11, 12, and 14 as most critical problems. Problems 1 and 10 deal with transportation problems. Problems 5, 6, 8, 11, 12, and 14 are concerned with administrative issues and information that respondents perceive that they receive from service providers. See Chart 1 below.

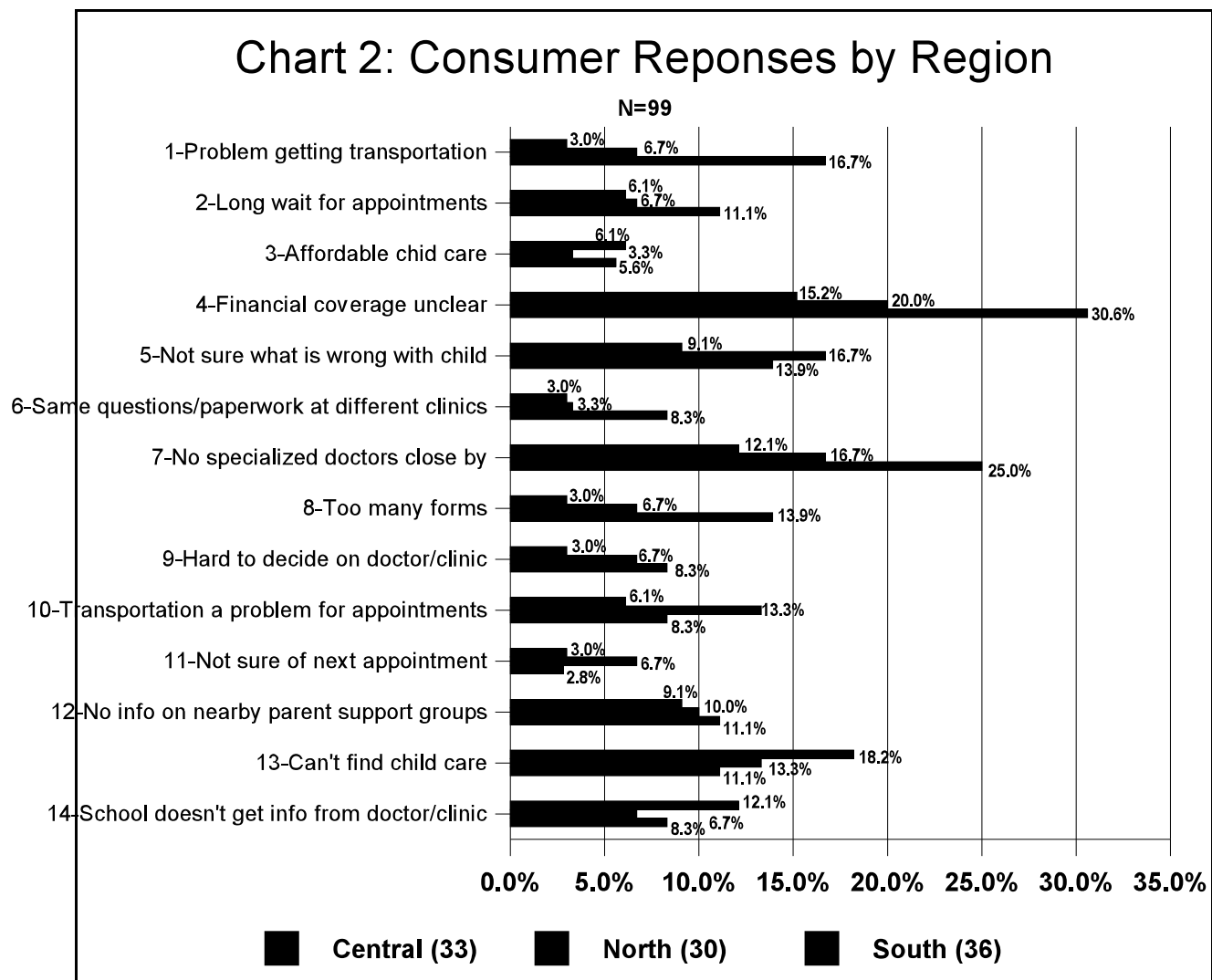


The most notable of the differences in answers by race was problem 14 - *School doesn't get info from doctor/clinic*, with the black respondents' choice as a critical concern being 7.2 times more than that of white respondents. Black parents were almost three times as likely to answer that Problem 1 - *Problem getting transportation* was a primary concern for them than white parents.

Also noteworthy is the congruency between black and white parents on four questions: Problem 2 - *Long wait for appointments*, Problem 4 - *Not clear what financial coverage is available to us*, Problem 7 - *There are not specialized doctors close by so we have to travel far for some*

appointments, and Problem 13 - *Can't find child care for my child with disabilities*.

To compare the respondents' answers by geographic regions, responses were grouped by residence in northern, central, or southern regions of the state corresponding to the state's Public Service Commission Districts. (See Appendix B for a map of the districts) When the 14 problems were considered by region (Chart 2), there was considerable variation among the southern, northern, and central regions in their "most critical" ranking of six of the problems—1, 4, 7, 8, 10, and 11. Problems 1, 7, and 10 deal with transportation while problems 4, 8, and 11 deal with perceived administrative issues.



The biggest difference by region was that of Problem 1 - *We have problems getting transportation for our children's appointments* which was noted as a most critical problem over five times more frequently in the southern part of the state than in the central. With the exception of Problem 13 - *Can't find child care* and Problem 14 - *School doesn't get info from doctor/clinic*, issues were stated as problems more frequently in the northern and southern regions which are geographically away from the central region where the concentration of

providers and services is the highest in the state. A review of issues considered critical by over 10 percent of respondents in each of the regions shows that consumers in the southern region exceeded others in the count of problems (eight) with the northern consumers following with six and the central region choosing only four.

Three issues noted most frequently as critical problems in all areas of the state were Problem 4 - *Not clear what financial coverage is available to us*, Problem 7 - *There are no specialized doctors close by so we have to travel far for some appointments*, and Problem 13 - *Can't find child care for my child with disabilities*.

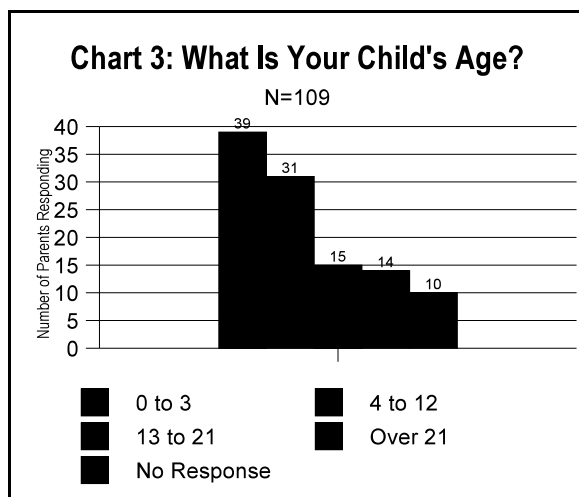
Two open-ended questions followed the first section. The first question asked parents to describe any other problem they had in caring for their child. Fifty-seven of the 109 surveys (52 percent of the total) had comments on this question. Answers included the following issues at the listed frequencies:

Table 8: Number and Percentage of Responses to Question - *Please describe any other problems you have in caring for your child.*

Problem	Number of Responses	Percentage
financial assistance	9	15.8%
transportation	8	14%
education	6	10.5%
child care	6	10.5%
diagnosis/referral/information	6	10.5%
health care services	5	8.8%
attendant care services	4	7%
equipment	3	5%
respite care	3	5%
job training and employment	3	5%
information	2	3.5%
assistive technology	1	1.8%
behavior	1	1.8%

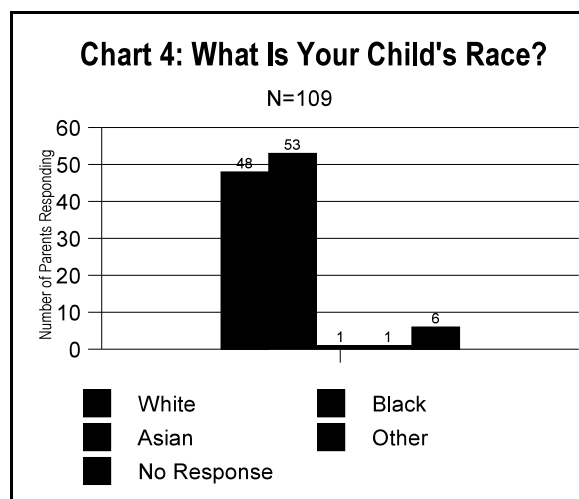
The second question asked parents to describe how genetic services had been helpful to them and their child. Fifty-two (47.7 percent of the total) of the 109 surveys had comments. Answers ranged from praise for the services and specific providers (22 responses or 20 percent of the total) to never having heard of the service (10 responses or 9 percent of the total). Some respondents clearly did not understand that they were being asked specifically about genetic services (11 responses or 10 percent of the total), their comments referred instead to other

services. All of the comments for both these questions are identified and attached at the end of this report. (See Appendix C and Appendix D)

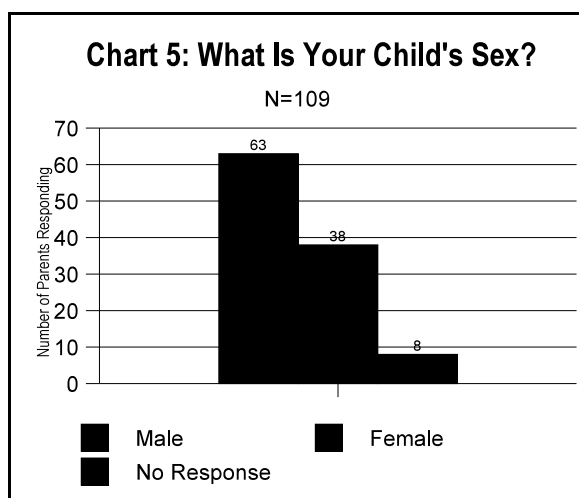


The survey closed with questions about the child with genetic or developmental disabilities. Parents were asked their child's age, sex, and race. Charts 3 through 5 reflect this information.

Chart 3 shows the ages of the children of the responding parents. Two-thirds (64 percent) of the parents responding indicated their children were ages birth to 12 years. Only 14 percent said their children were from 13 to 21 years old, this explains the absence of any comments on the survey on transitioning services for teens.



Of those answering the survey, 53 (48.6 percent) were black and 48 (44 percent) percent were white. (According to 2000 Census summary data prepared by the Annie E. Casey Foundation for their KIDS COUNT project, Mississippi's current population of 775,187 children under age 18 are 52.3 percent white, 45 percent black, .6 percent Asian, and 2 percent other. Nationally, 68.6 percent of the child population is white and 15.1 percent is black.)



Sixty-three the respondents (57.7 percent) had male children, while 38 (34.8 percent) had female children. (The KIDS COUNT 2000 Census data for Mississippi says 51 percent of the state's child population is male while 49 percent is female. National census data on disabilities shows that more male children have disabilities than female children. This reverses as the population ages, with more older individuals with disabilities being women.)

The final question was *What county do you and your family live in.* The parents responding lived in 47 of the state's 82 counties. Hinds and Madison Counties each had seven respondents for the highest county total, followed by Lauderdale and Oktibbeha Counties with five each. Many counties had only one parent responding.

Summary of Consumer Survey

The following issues were found to be important to the responding parents of children who require genetics services:

1. understanding availability of financial coverage
2. local availability of specialized physicians
3. child care
4. access to parent support groups
5. transportation

The results also showed that of the above listed issues, transportation and access to information were more frequently mentioned as problems by black parents. Racial differences in these perceptions are not surprising given the disparity in socioeconomic status between whites and blacks in Mississippi. Because respondents were not asked questions regarding income, their answers can not be definitely linked to this variable.

Geographic location also differentiated parents: those living in the southern and northern regions of the state cited accessibility issues (transportation, availability of specialized physicians), and understanding financial coverage more frequently as problem issues than parents living in the central region of the state. The differences are explained by the accessibility in central Mississippi to the state's tertiary care center at University Medical Center as well as the state's public and nonprofit human services support organizations. In the northern and southern portions of the state, such access is limited to those living near Memphis in the north and New Orleans in the south.

There were positive replies about the services which illustrate system strengths and indicate parental needs:

Genetics services have been a big help. When we call them they respond quickly.

Genetic screening of our child alleviated some of the concern that her condition was hereditary. Although her condition is genetic, it is a random occurrence condition.

At birth, genetic services were very helpful in explaining our diagnosis of Down syndrome.

Other parents used the opportunity of the survey to voice other concerns about caring for their children with disabilities.

When services are coordinated it is always helpful.

His advisor at school made his doctor's appointment and made sure we had a ride to the doctor.

My child has someone to come into my home to work with him on his speech and he says more words.

In closely reviewing all the questions answered on the parent survey, including the problems listed and the open-ended questions, only a small number of parents (9%) did not know about the genetics services available in Mississippi and had not used them.

The Provider Survey

The one-page Survey on Genetic Services in Mississippi to Providers (See Appendix E) was mailed to seven groups of providers in Mississippi including Mississippi Department of Health personnel, University Medical Center staff, staff of the Community Health Centers who are members of the Mississippi Primary Health Care Association, and members of the Mississippi Perinatal Association and the Mississippi chapter of the American Academy of Pediatrics. Surveys were mailed on varying dates: June 7, 12, 14, 20 and 22.

The groups and the number of surveys mailed were:

Table 9: Number and Percentage of Provider Surveys Mailed and Returned

Type of Provider	Number Mailed Out	Number Returned	Percentage Returned
Health Dept. Early Intervention staff	45	19	42%
Health Dept. County Health Department staff (Coordinating RNs)	50	48	96%
Community Health Centers Clinical Staff	71	20	28%
UMC Genetics Division Clinical staff	5	4	80%
UMC Pediatric Subspecialty MDs	102	30	29.4%
MS Perinatal Association	294	65	22%
Academy of Pediatrics/MS Chapter	288	28	9.7%
Total	855	208	24%

Question 1 asked providers if they saw patients who have birth defects and genetic disorders such as sickle cell, Down syndrome, spina bifida, galactesemia, cystic fibrosis, and hemophilia. Eighty-eight percent of those responding said “yes” while 6.7 percent said “no.” Eleven surveys did not have a response to this question. Distribution of provider types (Survey Question 7) is shown in Table 10 below. Over 50 percent (109) of respondents were physicians and 30 percent (62) were nurses. The remaining respondents were distributed among several other professional

categories.

Table 10: Number and Percentage of Provider Type Responding to Survey

Type of Provider	Number	Percentage
Doctor	109	52.4%
Nurse	62	30%
Early Intervention Specialist	16	8%
Nurse Practitioner	7	3%
Social Worker	6	3%
Dentist	1	.5%
Osteopathist	1	.5%
Registered Dietician	1	.5%
No Response	5	1.4%
Total	208	100

In the next section of the survey, Question 2, providers were asked about 16 issues that might be important in caring for patients with a genetic diagnosis. Providers were asked to rank the issues in the order of their importance, using “1” as the “most important,” “2” for the next most important, etc. Providers were asked to enter “NA” if the statement did not apply to their program.

The issues under Question 2 are numbered as on the survey 1 through 16 in the following table. In comparison to the parent surveys, few of the providers misunderstood the ranking system of this question, but the surveys that were completed with multiple 1s, 2s, or 3s were entered with the same rankings given to them by the respondents.

Table 11: Percentage of Providers Ranking Issues as Most Critical				
Issue	%Ranked 1st	%Ranked 2nd	%Ranked 3rd	% NA
1. Not enough skilled professionals.	12.5	12	4.3	51
2. Reimbursement rates insufficient for my services.	5.8	9.1	4.3	59.1
3. No transportation for our patients to get here.	12.5	11.5	7.7	45.2
4. Patient's eligibility for financial coverage not clear to me.	6.3	10.6	3.8	51
5. Overall management of patient is not coordinated among providers so there are duplications/gaps.	20.2	10.1	5.3	37
6. Incomplete information available on patients referred to me by other providers.	11.1	10.6	4.8	47.1
7. Not having specialized doctors available to refer patients close to their homes.	27.4	12	7.7	35.6
8. My office staff or I are required to fill out too many forms.	9.6	11.1	3.8	45.2
9. Lack of affordable child care for patient's children.	8.7	8.2	3.8	55.8
10. System of care is difficult to figure out/not sure how to refer patient for follow up.	8.2	12.5	4.3	49.5
11. Limited availability of training programs to keep my skills up to date.	14.4	5.8	3.8	51
12. Appointment keeping is a problem.	13	13	6.3	36.5
13. Other providers are not aware of nor do they understand what services we can provide.	13.9	8.7	5.8	41.8
14. Long wait for referral appointments for my patients to other providers.	9.6	13.9	5.3	42.8
15. Long wait for follow-up appointments for my patients here.	4.8	7.2	2.4	62.5
16. Do not have a list of support groups available for referral of parents in our area.	12.5	9.1	5.3	37
<i>Totals for rows do not add up to 100% because of multiple responses for each problem.</i>				

The issues most often ranked as top concerns were:

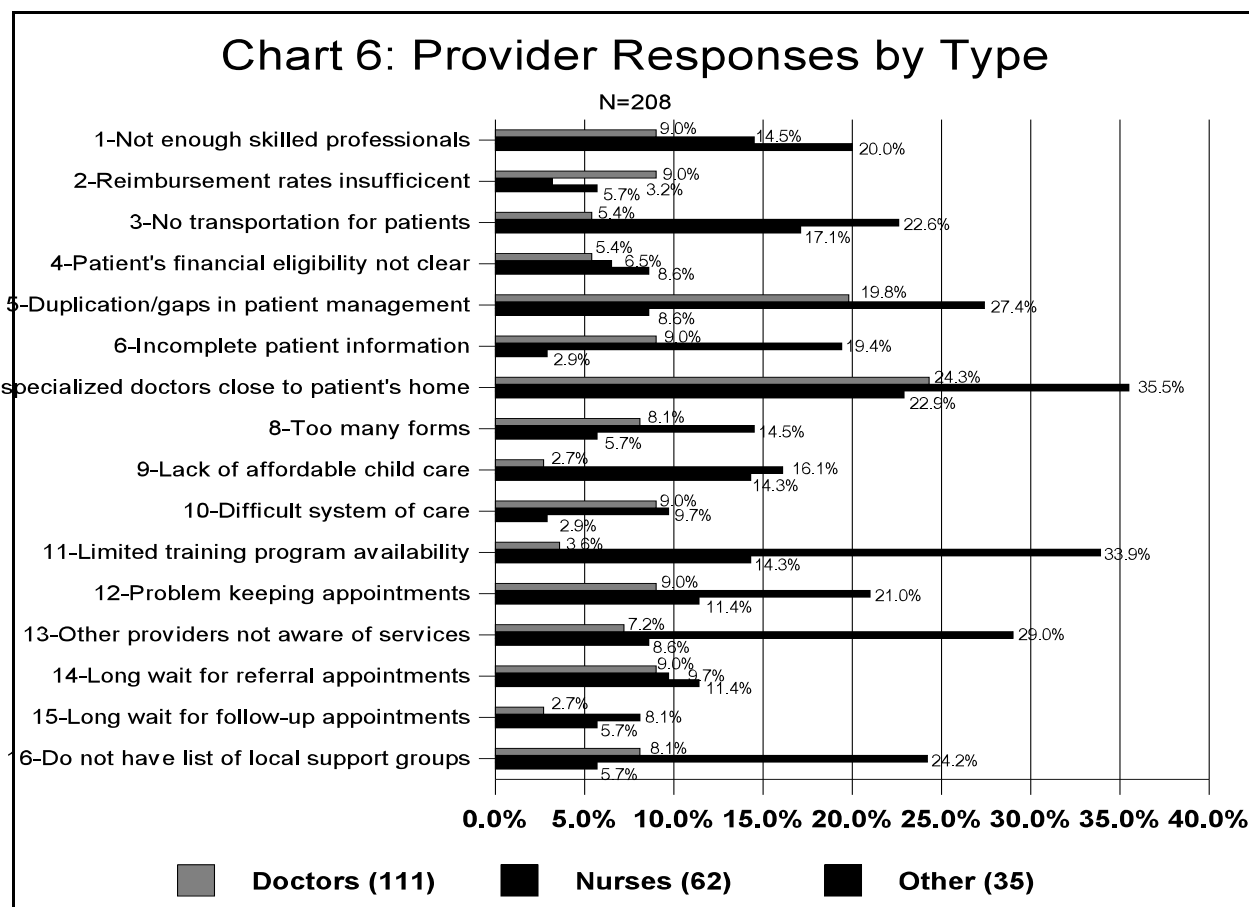
Issue 7 - *Not having specialized doctors available to refer patients close to their homes* at 27.4 percent,

Issue 5 - *Overall management of patient is not coordinated among providers so there are duplications/gaps* at 20.2 percent, and

Issue 11 - *Limited availability of training programs to keep my skills up to date* at 14.4 percent.

The respondents' answers to the 16 issues were also analyzed by provider type and by the region

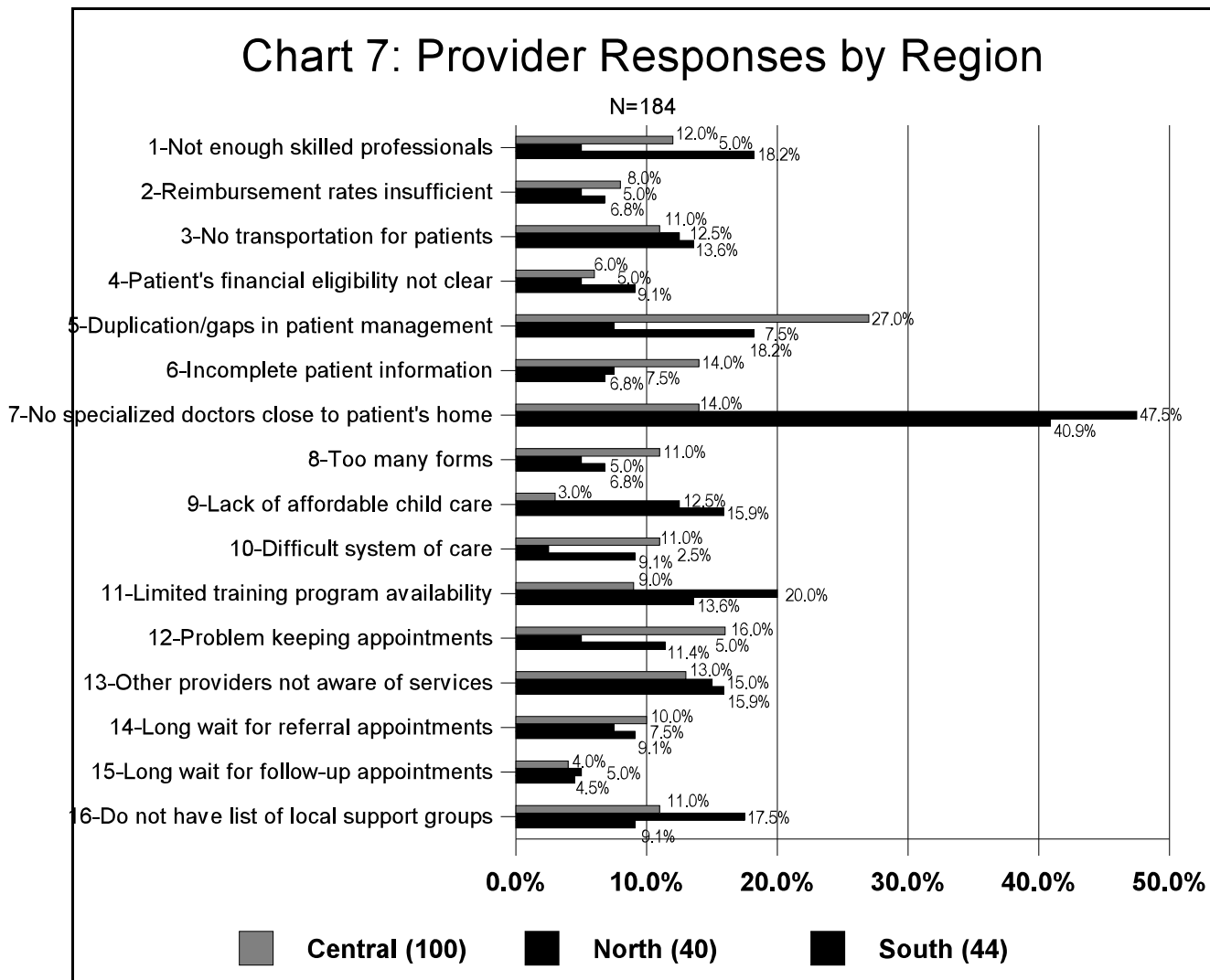
of the state in which they work. In the analysis of providers by type (Chart 6), answers were charted according to whether the respondent was a doctor, a nurse, or “other,” which included social workers, a dentist, and a registered dietician. There was considerable difference among one or more of the types of providers on 13 of the 16 issues.



Nurses expressed concern more frequently on 13 of the 16 issues than other providers, with dramatically greater frequency on seven of these issues. These issues included those related to patients—*no transportation, no specialized doctors close by, duplication/gaps in patient management, problem keeping appointments, no list of support groups*—and issues for nurses—*limited training programs*. Doctors chose two areas as more critical for them—*duplication/gaps in patient management* and *no specialized doctors close to patient's home*. Doctors lead only on one issue—*Reimbursement rates insufficient*. The group of “Other” often mirrored the nurses in their choices of critical issues but lead the critical answers for three issues—*not enough skilled professionals, patient's financial eligibility not clear, and long wait for referral appointments*.

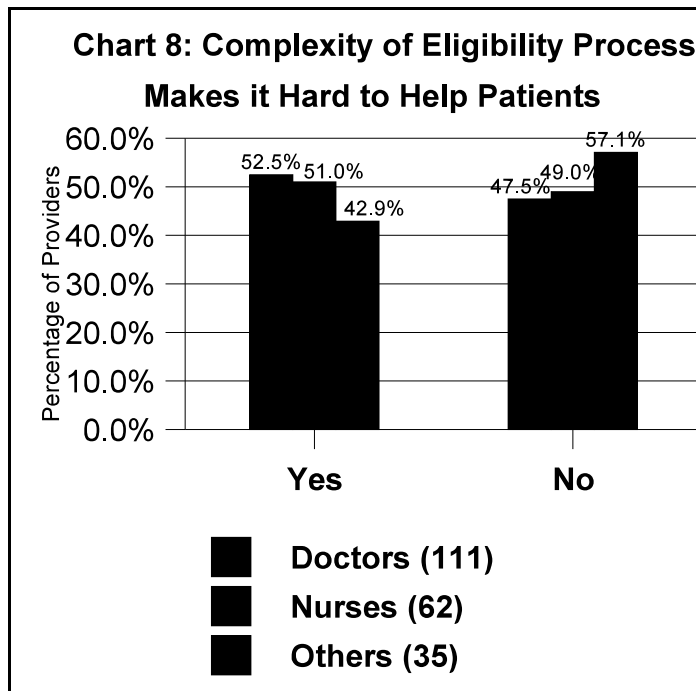
To compare the providers' answers by geographic regions, the respondents were placed in northern, central, or southern regions corresponding to the state's Public Service Commission Districts (See Appendix B). When provider answers to the 16 issues were considered by region (See Chart 7 below), there was some variation among the northern, southern, and central regions,

with the most dramatic difference expressed in Issue 7 - *No specialized doctors close to patient's home*: the providers in the more remote southern and northern regions expressed far greater concern than those located in the doctor and hospital rich central region. Yet the central region providers lead the way in concerns about *duplication/gaps in patient management*, *incomplete patient information*, *problem keeping appointments*, and *long wait for referral appointments*. The southern region respondents cited *not have enough skilled professionals*, *transportation*, and *lack of affordable child care* as their most critical issues while providers in the northern region cited *no specialized doctors*, *limited training program availability*, and *do not have list of local support groups*.



Question 3 asked providers if the complexity of eligibility determination process makes it hard for them to help patients. Providers were allowed a “yes” or “no” answer. Overall, this was an almost evenly split question with 50.6 percent of the providers answer “yes” and 49.4 percent answering “no.” When the data was further analyzed by type of provider (See Chart 8), there were some slight differences. Doctors and nurses answered the question almost equally with more “yes” than “no answers. “Other” providers answered somewhat differently than the other

provider groups. Over 42 percent of this group answered “yes,” while 57.1 percent answered “no.” This is a mixed group of professionals whose roles and experiences in assisting patients are highly variable hence their knowledge of eligibility requirements and financial assistance vary as well.



Questions 4 and 5 were open-ended questions. Question 4 asked *What problems do you see as critical in caring for patients with genetic disorders?* Eighty-three of the 208 providers (40 percent) responding had comments. Some responses were general—lack of resources, lack of education— and some were very specific:

We need a copy of the newborn genetic screening report in the infant’s chart of their primary care provider’s office.

Question 5 asked *What aspects of your program are especially helpful to patients and their families?* More than half of the providers, 105 out of 208 (50 percent), answered this question. Many good services were mentioned.

Health Department and social workers can help entire family and or referral.

We provide transportation, follow-up appointments are readily available, good referral base.

Try to educate whole families, making them aware of future considerations for child.

My program helps parents understand the disorders that their child may have with the help of our library to provide tapes, hand-outs, toys, etc. to help parents understand their child.

All of the answers to Question 4 and 5 are attached at the end of this report. (See Appendix F and Appendix G)

Question 6 asked providers to identify the county in which they provide care. Providers reported that they worked in 71 of 82 counties. Hinds County had the most providers—56.

The answers to Question 7, the final question, were discussed in the beginning of the provider section.

Summary of Provider Survey

Results of this survey show that respondents have the following major issues in caring for children with genetic conditions and disabilities:

1. insufficient skilled professionals for referrals
2. uncoordinated management and information regarding patient care
3. lack of training programs to maintain skills
4. lack of information for providers regarding service availability and parent support groups
5. transportation for patients

Differences in responses were observed among physicians, nurses, and other provider types. Nurses chose 12 issues more frequently than physicians and other providers as their most important issues, with seven showing a considerable difference from the other providers: *no transportation for patients, duplication/gaps in patient management, no specialized doctors close to patient's home, too many forms, limited training program availability, problem keeping appointments, other providers not aware of services, and do not have list of local support groups*. This finding is not unexpected given the typical role of the nurse in managing patient care and in counseling patients. Nurses are therefore more aware of patient service problems than doctors.

Differences in responses were also noted by geographic location of the provider. Service coordination and availability of specialized doctors were two issues mentioned most frequently as problems for the providers in the southern and northern portions of the state. As noted earlier these observation are related to the lack of accessible tertiary care specialists in southern and northern Mississippi and the presence of a tertiary medical center in central Mississippi.

Open-ended comments included general complaints about the lack of resources, lack of education, and a specific request for follow up on the newborn genetic screening form for primary care providers. In reviewing the answers to this survey, it is apparent that the health care providers who responded to the survey are aware of their limitations in providing care to individuals with genetic disorders and developmental disabilities. While these limitations may vary from setting to setting, the issues remain interconnected. Some issues are the same faced by professionals serving all patients—lack of resources, follow-up and support, lack of service providers, timely appointments, Medicaid—particularly elderly patients and those living in poverty. Yet other issues are especially critical as services for people with disabilities—transportation, provider training in genetic disorders, awareness, care coordination.

The answers providers furnished to the question of the helpful aspects of their programs (Question 5) indicate that providers are searching for and implementing priorities and programs that can work for people with genetic disorders and their families. Providers mentioned assistance with transportation and equipment, coordination of services, follow-up appointments, resource and referral, and education and training.

The Administrator Survey

The one-page Survey on Genetic Services in Mississippi to Administrators (See Appendix H) was sent to eight groups of administrators in Mississippi including Mississippi Department of Health personnel, University Medical Center staff, and the Community Health Centers. Surveys were also mailed to Division of Medicaid staff. Surveys were mailed on varying dates: June 5, 7, 11, 12, and 22.

These groups and the number of surveys mailed were:

Type of Administrator	Number Mailed Out	Number Returned	Percentage Returned
Health Dept. Genetics staff	7	6	85.7%
Health Dept. Perinatal High Risk Management administrative staff	27	7	25.9%
Health Dept. Early Intervention administrative staff	9	6	66.7%
Health Dept. Children's Medical Program administrative staff	4	2	50%
Health Dept. County Health Department administrative staff	18	7	38.9%
Community Health Center Directors	20	10	50%
UMC Genetics Division administrators	3	2	66.7%
Division of Medicaid administrator	1	1	100%
Total	89	41	46%

Question 1 asked administrators if their program served patients with birth defects and genetic disorders. All the administrators answered that their program served patients with genetic disorders. Question 2 of the survey presented administrators with 16 issues that might be important in caring for patients with a genetic diagnosis. Administrators were asked to rank the issues in the order of their importance, using "1" as the most important in their program's work with patients, "2" for the next most important, etc. Administrators were asked to enter "NA" if

the statement did not apply to their program. The results are shown on the following table for each of the issues listed in the order shown on the survey.

Again in comparison to the parent surveys, few of the administrators misunderstood the ranking system of this question, but the few surveys that were completed with extra 1s, 2s, or 3s were entered with the same rankings given to them by the respondents. The issues asked of administrators are the same as those asked of providers.

Table 13: Percentage of Administrators Ranking Issues as Most Critical				
Issue	%Ranked 1st	%Ranked 2nd	%Ranked 3rd	% NA
1. Don't have available enough skilled professionals to staff program.	30	25	7.5	25
2. Reimbursement rates insufficient for our services.	12.5	17.5	2.5	35
3. Transportation to our location is a problem for our patients.	47.5	17.5	7.5	12.5
4. Availability of financial coverage for our patients not clear.	10	22.5	7.5	25
5. Overall management of patient services is not coordinated among providers.	17.5	22.5	12.5	5
6. Incomplete information available on patients referred to our program from other providers.	22.5	7.5	0	20
7. Not having specialized doctors available for referral of our patients close to their homes.	27.5	20	12.5	15
8. My office staff or I are required to fill out too many forms.	10	17.5	2.5	35
9. Lack of affordable child care for patient's children.	12.5	10	5	35
10. System of care is difficult to figure out/not sure how to refer patient for follow up.	5	12.5	7.5	32.5
11. Limited availability of training programs to keep our staff skills up to date.	17.5	12.5	7.5	22.5
12. Appointment keeping is a problem for our program.	22.5	20	7.5	15
13. Other providers not aware of nor do they understand our services.	17.5	17.5	0	17.5
14. Long wait for referral appointments for our patients to other providers.	5	15	10	27.5
15. Long wait for follow-up appointments for our patients here.	2.5	12.5	5	45
16. Do not have a list of support groups available for referral of parents.	20	15	2.5	20
<i>Totals for rows do not add up to 100% because of multiple responses for each problem.</i>				

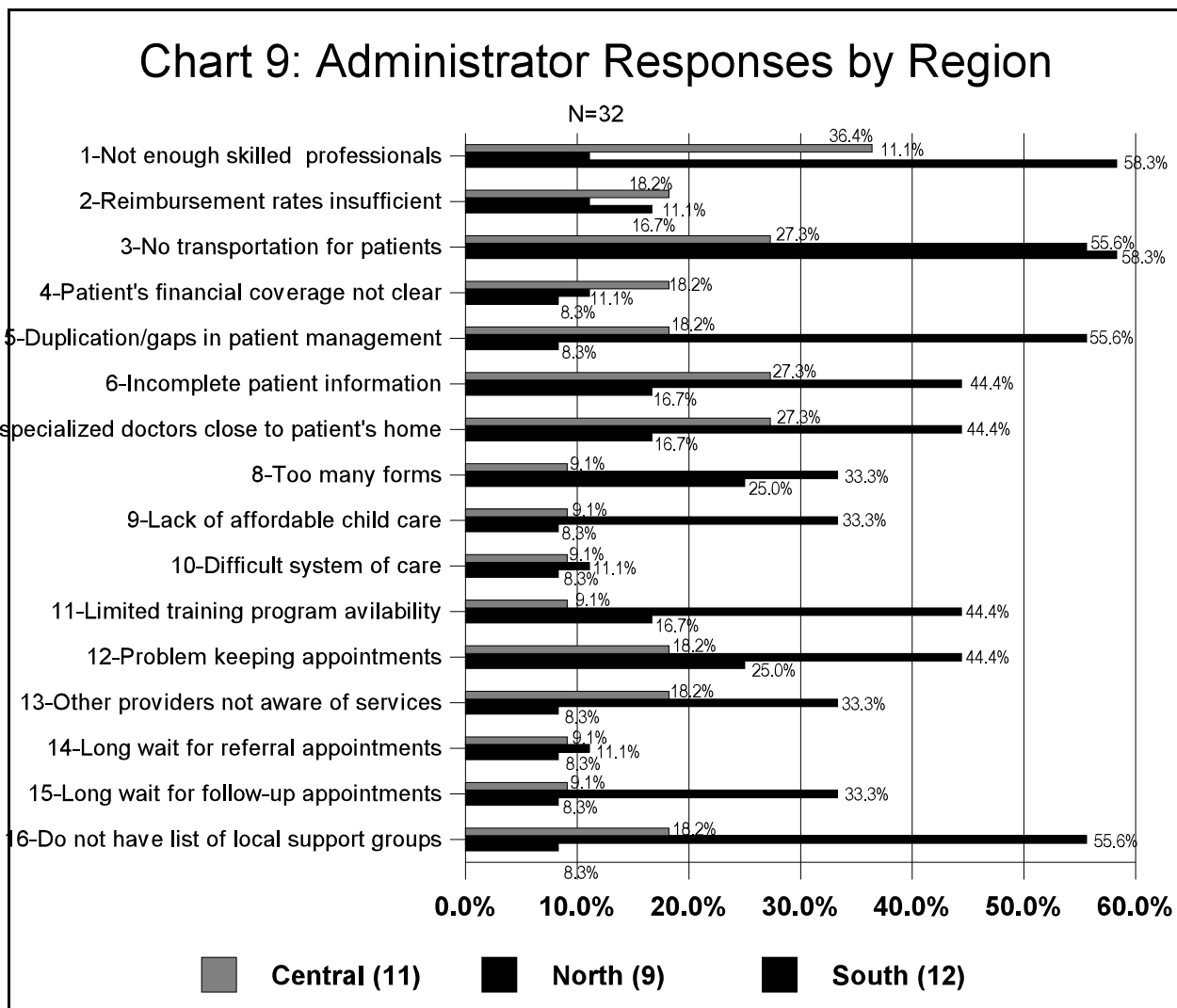
The issues chosen most often by administrators as their number 1 problems were:

Issue 3 - *Transportation to our location is a problem for our patients* with 47.5 percent choosing this issue.

Issue 1 - *Don't have available enough skilled professionals to staff program* at 30 percent, and

Issue 7 - *Not having specialized doctors available for referral of our patients close to their homes* at 27.5 percent.

Administrators' answers to the 16 issues in Question 2 were compared by geographic regions with responses placed in northern, central, or southern regions corresponding to the state's Public Service Commission Districts. (See Appendix B) There was considerable difference among regions, especially in comparing north and south to central in their "most important" ranking of 11 of the issues (Chart 9 below). These issues were relevant to improving access to services for patients—the availability of skilled professionals, transportation, lack of affordable child care, appointments, and support groups. Responses to these issues were expressed more frequently by administrators located further away from the central region of the state where the tertiary care center is located.



Responses to issues 5 (care management) and 16 (local support groups) were the most varied among the three regions. Responding administrators in the northern counties of the state were 6.7 times more likely than respondents in the southern area of the state to list these issues as their first choices. These issues concerned case management and local parent support groups. The northern region led the other regions on declaring 12 of the issues as most critical, while the southern region only twice led the others in most critical issues. The central region led the other regions on only two issues. Administrators from all regions ranked Problem 3 - *No transportation for patients* as a critical issue, but not surprisingly the northern and southern region administrators responded at a rate double that observed centrally.

Question 3, a “yes” or “no” question, asked administrators if the complexity of the determination process made it hard for their staff to help patients. Almost three-quarters or 72.7 percent of administrators answered “no” to this question.

Question 4 was an open-ended question: *What problems do you see as critical in managing your program for patients with genetic disorders?* Twelve of the 41 responding administrators had comments. Transportation, referral, and awareness were all issues mentioned. Question 5 was also an open-ended question: *What aspects of your program are especially helpful to patients and their families?* Twenty-six of the 41 responding administrators answered this question. Those responding mentioned case management and referral as well as service issues. These comments are marked and attached at the end of this report (See Appendix I and Appendix J).

The administrator survey concludes with Question 6 asking the county in which the administrator’s program is located. Administrators reported that their clinics were in 36 counties and five different Health Department districts.

Summary of Administrator Survey

In summary, the administrators’ list of problem issues can be summarized as follows:

1. transportation for patients
2. availability of skilled professionals within the program and for local community referrals (This would include training program availability.)
3. patient care management issues: insufficient information from other providers, excessive paperwork
4. financial coverage: insufficient reimbursement and information regarding financial assistance for patients
5. Affordable child care for families

Analysis of administrators’ responses by geographic region demonstrated that issues that touched on services to clients—the availability of skilled professionals, transportation, and support group information—were of greater concern (greater by 50 percent) away from the more populated central region of the state.

Administrators’ open-ended answers touch upon issues affecting both the parents and providers. The very work they do places administrators in a unique position of influence that can make a significant impact in the areas of both awareness and service. In reviewing the completed

administrators' surveys, it seems this group has taken the concerns of both the patients and the providers into consideration in their answers, and rightly so, since they routinely see the viewpoint of both groups in their positions as administrators. While the administrator list of issues in Question 2 was identical to the provider list, the two groups had only one similar answer in the top three choices of important issues: *Not having specialized doctors available for referral of patients close to their home*. This was the top choice of importance for providers and was third among the three most important issues for administrators. This issue was the second most critical issue chosen by parents. Administrators chose *Transportation to our location is a problem for our patients* as their top concern choice, a choice parents did not include at all in their top three concerns.

Survey Summary

A comparison of issues ranked most problematic by consumers, providers, and administrators (Table 5) demonstrates that on the whole there is congruency in their choices with only a few unique issues chosen by each group. Availability of specialized physicians in areas of the state that are far away from tertiary care centers consistently appears as a concern for consumers and administrators (as “2,” next to the most critical) and for providers (as “1,” the most critical). Management issues (availability of information on patients, excessive paperwork) appear on the provider list (“2”) and the administrator list (“3”). Note that consumers ranked a related issue—their poor understanding of financial coverage—as the number one problem. Transportation is last on the list for consumers and providers but first for administrators. Financial coverage issues (including process complexity, and insufficient reimbursement) also appear first for consumers and fourth for administrators. Information and availability of parent support groups is another major issue of concern that is mentioned in open ended answers and is ranked highly by consumers and providers.

Table 5: Comparison of Issues Ranked Most Important by Consumers, Providers, and Administrators		
Consumer List	Provider List	Administrator List
Understanding financial coverage	Insufficient skilled professionals	Transportation for patients
Local availability of specialized physicians	Uncoordinated management and information regarding patient care	Availability of skilled professionals within the program and for local community referrals (and this would include training program availability)
Child care	Lack of training programs to maintain skills	Patient care management issues: insufficient information from other providers, excessive paperwork
Access to parent support groups	Lack of information for providers regard service availability and parent support groups	Financial coverage: insufficient reimbursement and information regarding financial assistance for patients
Transportation	Transportation for patients	Affordable child care for families

SURVEY ON GENETIC SERVICES IN MISSISSIPPI

We want to improve services for Mississippi residents with genetic and developmental disorders. To make these improvements, we need to hear from you about your experiences. Please answer these questions and then write down any additional suggestions on services that are not covered.

Please check any problems that you or members of your family have encountered. Next, enter the number 1 by the most critical problem for you, the number 2 by the next most critical, the number 3 by the next, etc.

Write NA if this issue was not a problem for you.

- ____ ☐ We have problems getting transportation for our children's appointments
- ____ ☐ We have to wait a long time to get an appointment for our children.
- ____ ☐ There is a problem finding affordable child care for our other children when we have appointments.
- ____ ☐ Not clear what financial coverage is available to us.
- ____ ☐ Not sure what is wrong with my child and how it happened.
- ____ ☐ We sometimes get the same questions and paperwork at different clinics or doctor's offices.
- ____ ☐ There are no specialized doctors close by so we have to travel far for some appointments.
- ____ ☐ We have to fill out so many forms each time we go to the clinic.
- ____ ☐ It is hard to figure out which doctor or clinic to go to for our child's care.
- ____ ☐ Because of my transportation problems I sometimes have a hard time keeping appointments
- ____ ☐ Not sure when we have to go to the doctor again.
- ____ ☐ We have not received information on parent support groups near where we live.
- ____ ☐ Can't find child care for my child with disabilities.
- ____ ☐ Our child's school doesn't get information from our doctor/clinic.

Please describe any other problems you have in caring for your child. _____

Please describe how genetic services have been helpful to you and your child _____

Please tell us about your child with genetic/developmental disabilities:

When was your child born? _____

What is your child's sex: Male or Female

What is your child's race?

White

Black

American Indian

Asian, Pacific Islander, Southeast Asian

Other _____

What county do you and your family live in? _____

Thank you! Please return in the stamped addressed envelope provided by June 25.

[illegible]

Survey on Genetic Services in Mississippi to Consumers

Please describe any other problems you have in caring for your child.

(N/A = No Response)

1. We are local to the University Medical Center which is where my child is being treated for Sickle Cell so we don't have any problems with any questions on this survey.
2. N/A
3. My child has a genetic disorder called Sickle Cell. He takes medication but sometimes experiences pain and swelling and is taken to UMC in Jackson.
4. I have no problems with my child's doctors or clinic appointments.
5. N/A
6. We have always had problems getting to the doctor; No help at all getting there.
7. None
8. N/A
9. None
10. She fights her teachers. Also she throws tantrums; she bites the teacher and her behavior is really bad and she pushes down her clothes.
11. They said because of my income I can't get any help. So I can't answer any question. Don't understand this.
12. N/A
13. N/A
14. N/A
15. My child's genetic disorder was treatable, but we did not get a diagnosis until 1 month after his death.
16. I am very concerned about the special education programs in the school district in which we live. The center that I feel would serve my child's needs is an hour long drive from our home.
17. My problem in caring is eye vision. I am trying to get her on a check because of that, but could you help me. Please.
18. N/A
19. There is no one out there it seems that wants to help at all finding out any kind of info that might help my family or my little girl.
20. N/A
21. N/A
22. Getting him to eat because for so long he has had a problem with vomiting. Now he doesn't want to eat.
23. N/A
24. When she eats she swallows her food...she doesn't chew it; and when she eats sometimes she gets choked on her food.
25. N/A
26. N/A
27. N/A

28. I would like to find a day care center that allows drop-ins.
29. N/A
30. N/A
31. N/A
32. N/A
33. N/A
34. N/A
35. To get necessary physical devices available for my child and others to learn to walk.
36. It is hard holding him because he weighs so much and can't walk.
37. N/A
38. We need childcare available/affordable for our children who are single moms. Please. Thank you.
39. N/A
40. N/A
41. N/A
42. N/A
43. Financial help for my child who has a speech problem and behavior. He doesn't qualify for SSI.
44. N/A
45. I would like to see and I get Disabilities for Earl because he has developmental disorders.
46. N/A
47. N/A
48. N/A
49. Our greatest problem is getting schools to accept outside reports from physicians, psychiatrists, physiologists, etc. Services that my child needs – Finding good qualified OTs and PTs and Speech Therapists
50. There are none. I have been very active in learning about my child's genetic disorder.
51. With Jesse, getting him to and from therapy...taking Jesse to and from Special Olympics and to outings for special kids.
52. We now use doctors in MS but at birth were not referred to anyone. We were not informed about services at health dept. We still consult with out of state therapists who are in close contact with therapists at Dupont Hospital who are very knowledgeable of our son's problem.
53. Attendant care services
54. Transportation problems -- most times I ride with someone. This community needs services--we need training, workshops, to educate us on how to care for a child.
55. There are not enough financially supportive programs in Mississippi for single parents of disabled children.
56. N/A
57. I cannot get the ABA/one on one therapy--tutor that he needs because there is none available here in our area (public school). The special ed has not got the type of services that my son needs. I have to teach him myself.
58. Getting physical therapy for our child in this school system
59. There is no childcare available or summer programs that specialize in disabilities.
60. No funding for van lifts, bath aids, etc. for children with physical disabilities.

61. N/A
62. Both parents work hard to find childcare.
63. He sleeps with me so I can feel him having seizures. I wished someone could make something that would connect to him and go off like an alarm is he has a seizure. And I am up on and off all night.
64. My daughter is 23 and we have a lot of problems with appointments, schooling.
65. N/A
66. Respite care
67. Childcare or after school care is the most critical -- the school or community doesn't provide it.
68. N/A
69. Closest genetic clinics is 2 hours away and the geneticist only works a few months per year--very hard to get appointment with her--hard to work around other MD appointments which makes us have to make many trip to Memphis each year. That uses up all our vacation time and we loose work hours which then makes it hard financially!
70. N/A
71. N/A
72. Appropriate training for her and appropriate living situations have always been the problems needing attention
73. I think that SSI and/or Medicaid should be for all children with disabilities. I do not think that parents should have to worry about losing Medicaid.
74. N/A
75. N/A
76. N/A
77. Childcare while I work -- how to handle behavior issues--biting, etc.
78. We have problems when she is hospitalized--someone to stay with her.
79. N/A
80. My son has to have constant supervision due to his severe epilepsy. He also has chronic pancreatitis and neurogenic bladder which requires cath.
81. Our child is now 18 and we have worked through a lot of these problems, but it was a struggle. Child now lives at North MS Regional Center preparing to live in a group home.
82. N/A
83. Services (medical) not available in this area of MS
84. It's better now, but I know when he was small (infant) we could have used a respite nurse for a short break (Didn't know if that was available). Family was scared to care for our special needs child. We never got a break.
85. There is no public transportation in my community. My child just graduated high school. No transportation for a job or college (except me!)
86. N/A
87. N/A
88. N/A
89. Respite care should be more accessible; I believe the guidelines should be relaxed. They are too stringent.
90. N/A

91. N/A
92. N/A
93. My child is 9 years old and still in diapers. Medicaid used to pay for diapers, but we lost Medicaid coverage since I'm working and we are over the financial limit for SSI. We are reapplying for Medicaid, but it is a very complicated process.
94. She is high level LDD/PDD with extreme impulsiveness. Most people do not want or feel she has a need for close watching but she does!
95. Child has a genetic disorder—he was tested in May. Won't get the results until Aug. Doctors don't explain the problem.
96. N/A
97. I am the student with depression. The major problems in Mississippi I face is health care. That is trying to pay for it. And transportation. Another major problem for me is my vocational rehabilitation counselor. I have problem getting to his office because of lack of transportation. So he hasn't been able to help me to pay for my depression medication.
98. N/A
99. I thought "patterning" was what physical therapy does. It is not. This is the only noninvasive treatment that works for neurologically impaired children. Why doesn't medical professional do it? I knew from teaching Sp. Ed. it was important. Every child needs to crawl blind or neurologically involved. (?) Why isn't it encouraged?
100. My son had many problems—right now he has had a great deal of trouble finding a job—no one will hire him because of his disability—CP
101. Insurance for health care CHIPS does not apply because I make 1 dollar too much.
102. N/A
103. I wish the hospitals and doctors had been more forth-coming when my child was born. I have a problem with the self-contained education setting in school.
104. Access to special services such as OT-PT-SP without long travel. Cooperation of school system with providing special services being received previously or before school entry. Also, includes special medical care.
105. The problems listed do not apply to us. We have received a great deal of support through our early intervention coordinator, Tim Seese, that has opened many doors. Our main issue is dealing with health insurance and the paperwork they require. It is amazing that I continually must justify the need for OT/PT/Speech for a child with Cerebral Palsy.
106. What does she do after she reaches 21? Consistent follow-up is not set up for these children who become young adults.
107. None
108. Need a list of problems that can occur and how do we solve them...more workshops needed, explain the medication and care given with more details.
109. N/A

Survey on Genetic Services in Mississippi to Consumers

Please describe how genetic services have been helpful to you and your child.

(N/A = No Response)

1. I've never heard of this service and I don't know what service is provided.
2. N/A
3. N/A
4. It keeps me updated with her health and well-being.
5. N/A
6. N/A
7. It's helpful because he hasn't been sick in the hospital since he has been receiving genetic services.
8. Transportation to doctor
9. It has been helpful to me by letting me know what is wrong with my children.
10. Been poor, been happened (?)
11. I receive Children's Medical Program (CMP) through Mississippi State, Dept. of Health.
12. None
13. N/A
14. N/A
15. N/A
16. Liza Van Norman, the PEDS team, First Steps, and the Children's Center at USM have all contributed to the progress my child has made. We are VERY grateful to Cindy Bivens and T.J. Shappley, and the Children's Center at USM!!
17. Well I just knew about it a month ago, but I understand you all are very helpful to your clients.
18. N/A
19. They have not been as far as I know.
20. N/A
21. It was very helpful getting my child's medicine in time for her RSV shots.
22. I believe the low weight gain is a genetically inherited, but the other I have no clue.
23. N/A
24. But I know Ms. Betty Minor from Early Intervention Program did an evaluation on Angelica
25. It has helped my child tremendously. Thank God.
26. He has a speech therapist, occupational therapist, and physical therapist.
27. N/A
28. N/A
29. N/A
30. Dr. Bock saw our son once and the appointment was rescheduled three times and an hour away from our home. My son is only 7 months old. We have our own transportation and private insurance at this time so many of these situations do not apply to us at this time but could change in the future.

31. N/A
32. N/A
33. N/A
34. My child has someone to come into my home to work with him on his speech and he says more words.
35. To help me learn the other therapy programs available.
36. N/A
37. Convenient and very helpful–no complaints.
38. N/A
39. I don't know anything about genetic services or exactly what it is.
40. N/A
41. N/A
42. N/A
43. N/A
44. My child has a speech and language delay. The weekly sessions have been helpful in getting us to focus on certain areas.
45. His speech is a little better.
46. N/A
47. N/A
48. It has helped my son get stronger than he was. It has helped me a lot by improving my son as he goes alone.
49. Unknown–due to child being adopted
50. Financially, I couldn't have afforded the services my child needed if not for services that were made available to us.
51. By providing some form of transportation so I can get my child to and from therapy and to special places.
52. N/A
53. N/A
54. N/A
55. My child's disabilities are due to prematurity, not genetic problems.
56. N/A
57. N/A
58. N/A
59. N/A
60. They weren't!
61. N/A
62. N/A
63. I don't know what genetic services are.
64. Genetic services have been a big help. When we call them they respond quickly.
65. This is the first time I heard about this service. I look forward to learn about the services.
66. We traveled to Memphis for our genetic services.
67. N/A
68. N/A
69. Help us to know what to look for.
70. N/A

71. N/A
72. I'm not aware of any "genetic services" or anything they have done for us or our child?
73. At birth, genetic services were very helpful in explaining our diagnosis of Down syndrome.
74. N/A
75. We, in Starkville, have been so fortunate about the care we receive. The Health Dept. has assisted us with all we have needed to do to obtain Medicaid and the T.K. Martin Center and its therapists have been great.
76. N/A
77. Didn't even know about this until today--no help so far.
78. Very helpful
79. No comment
80. I do not know of any help from genetic services.
81. We have had no genetic services.
82. N/A
83. Yet to be determined
84. Our child is functioning at a higher level than ever expected.
85. N/A
86. N/A
87. N/A
88. N/A
89. We are not aware of any such services.
90. N/A
91. N/A
92. We have come a long way now, he used to be uncontrollable.
93. Genetic screening of our child alleviated some of the concern that her condition was hereditary. Although her condition is genetic--it is a random occurrence condition.
94. N/A
95. Haven't been helped.
96. N/A
97. MSU campus has had increasing awareness. Getting through school is becoming somewhat easier.
98. N/A
99. N/A
100. N/A
101. N/A
102. His adviser at school made his doctor's appointments and made sure we had a ride to the doctor.
103. When services are coordinated it is always helpful. Dealing with a child with a disability is stressful, but if services are coordinated it helps.
104. Early intervention is provided at early stages, but once school-age evolves, services seem to diminish. First Steps very helpful.
105. N/A
106. As far as I can remember--we never had genetic services.
107. I have no idea what genetic services are.
108. N/A

109. N/A

SURVEY ON GENETIC SERVICES IN MISSISSIPPI TO PROVIDERS

We want to improve access to genetic services in Mississippi. To make these improvements, we need to hear from you about your experiences as a provider. Please answer these questions about services and then write down any additional suggestions on services that are not covered.

1. Do you see patients who have birth defects, genetic disorders (for example: sickle cell, Down syndrome, spina bifida, galactesemia, cystic fibrosis, hemophilia, etc.)? Circle one: Yes or No.
2. The following issues may be important in caring for patients with these diagnoses. Please rank the issues shown in the order of their importance in your work with these patients: enter 1 by the issue you perceive as most important, 2 for the next most important, etc. If the statement does not apply to your program please enter NA.

- Not enough skilled professionals in our work place.
- Reimbursement rates insufficient for my services
- No transportation for our patients to get here
- Patient's eligibility for financial coverage not clear to me
- Overall management of patient is not coordinated among providers so there are duplications/gaps
- Incomplete information available on patients referred to me by other providers.
- Not having specialized doctors available to refer patients close to their homes.
- My office staff or I are required to fill out too many forms.
- Lack of affordable child care for patient's children
- System of care is difficult to figure out: Not sure how to refer patient for follow up
- Limited availability of training programs to keep my skills up to date
- Appointment keeping is a problem for our program.
- Other providers are not aware of nor do they understand what services we can provide
- Long wait for referral appointments for my patients to other providers.
- Long wait for follow-up appointments for my patients here.
- Do not have a list of support groups available for referral of parents in our area

3. Complexity of eligibility determination process makes it hard for me to help patients.

Circle one: Yes or No

4. What problems do you see as critical in caring for patients with genetic disorders? _____

5. What aspects of your program are especially helpful to patients and their families _____

6. Please tell us the county in which you provide care _____

7. What type of service provider are you? Please circle: MD SW RN RD EIS PT OT

Thank you! Please return in the stamped addressed envelope provided by June 25.

Survey on Genetic Services in Mississippi to Providers

4. What additional problems do you see as critical in caring for patients with genetic disorders?

(N/A = No Response)

1. N/A
2. Lack of resources or the knowledge of
3. N/A
4. N/A
5. N/A
6. N/A
7. N/A
8. I don't have a problem with genetics, because I am readily available and provide services regardless of ability to pay.
9. N/A
10. N/A
11. N/A
12. N/A
13. N/A
14. We don't always get results of newborn screens-only health department does.
15. N/A
16. N/A
17. N/A
18. N/A
19. Patient information and education of problems associated with becoming pregnant and predicted outcomes.
20. N/A
21. N/A
22. Pt. handouts written in a language they can understand are scarce, sometimes not available.
23. Family support, respite
24. Lack of family understanding, very complicated issues, not prepared for end of life issues
25. N/A
26. Specialized tests not available on site, no access to genetics specialist
27. N/A
28. Early diagnosis and counseling about the disease and future pregnancies
29. N/A
30. Newborn screening reports (positive and negative) are not sent to the primary care provider to assist in case management.
31. We need a copy of the newborn genetic screening report in the infant's chart of their primary care provider's office.
32. We need to have available a list of providers, PT/OT/ST specialized in this field,

- procedures on referrals, et.al.
33. N/A
 34. Good follow-up and support
 35. N/A
 36. N/A
 37. N/A
 38. Hard to get through to specialty clinics, except sickle cell clinic
 39. None
 40. The parents of our patients often lack motivation to participate in services that would be beneficial or they often have unreasonable expectations about outcomes.
 41. N/A
 42. N/A
 43. N/A
 44. N/A
 45. N/A
 46. Easier to drive to Mobile or New Orleans from the Coast
 47. N/A
 48. N/A
 49. N/A
 50. N/A
 51. Very time consuming due to multiple needs and red tape; expensive (secretarial overtime, long distance phone calls, etc.)
 52. Transportation for families to subspecialists, therapists, etc.
 53. N/A
 54. N/A
 55. N/A
 56. Lack of education; long distance to travel for specialized care
 57. N/A
 58. N/A
 59. N/A
 60. N/A
 61. Lack of pediatricians in underserved counties who will provide basic care and make referrals accordingly.
 62. If a newborn doesn't follow-up with me after discharge, and has an abnormal screen (PV-U, SC, Thyroid, Gal), how do I know they've been contacted and have medical follow-up with someone?
 63. N/A
 64. Finding MD who take Medicaid very difficult; needs list of participating subspecialists
 65. N/A
 66. If patient requires more than one specialty physician, difficulty comes with trying to coordinate those visits into one date to travel out of town.
 67. N/A
 68. N/A
 69. N/A
 70. N/A

71. No standard management plan for the handicapped.
72. Parents education on child disease is very lacking; parents have strong cultural beliefs(?)
73. N/A
74. More information is needed about which interventions are effective, especially PT and OT.
75. N/A
76. N/A
77. N/A
78. N/A
79. N/A
80. Lack of competent service providers (e.g. PT, OT, Speech) at local level
81. N/A
82. N/A
83. N/A
84. N/A
85. Speedy referral for initial diagnosis
86. N/A
87. N/A
88. N/A
89. Some physicians do not refer children to health department for First Steps, PHRM, Genetics, CMP, etc. They are informed of programs.
90. N/A
91. N/A
92. Getting patient signed up for Disability and Medicaid. Patients see so many Disability families can't keep names, numbers and appointment dates straight.
93. N/A
94. Parents have to wait too long for an appointment.
95. N/A
96. Families are not educated as to the importance of genetics. Many families are afraid to admit having genetic disorders in the lineage.
97. Families and providers (OT, PT, ST) need to know more about how the disorder impacts growth and development.
98. Unsure at this time
99. Communication concern with local genetic RN and clerk
100. N/A
101. N/A
102. N/A
103. Timely appointments with the professionals that specialize
104. Not enough service providers!
105. N/A
106. I think it would be helpful if the community health centers in rural counties (i.e. Sharkey, Humphreys, Issaquena) had information on how to refer families to the genetics program in Health departments.
107. N/A
108. Coordination of appointments (timing and length between)

109. N/A
110. Nursing updates
111. N/A
112. N/A
113. N/A
114. As county health department, most of these are not applicable as we strictly refer or provide education or meds.
115. N/A
116. N/A
117. Education of family—caregivers
118. N/A
119. N/A
120. I would like to see more social services involved; due to limited staff social services are limited.
121. N/A
122. N/A
123. N/A
124. N/A
125. MS State Department Health has very good identification and follow-up process
126. Handouts to parents on specific disorders
127. N/A
128. N/A
129. Our knowledge base is limited on genetic disorders; need more teaching material on specific disorders or a referral system to get info for us to share.
130. Not enough knowledge of services other than HD services
131. N/A
132. N/A
133. Not enough help for older children and adults
134. N/A
135. We need closer (in-house) networking with Early Intervention
136. Lack of knowledge and understanding of many genetic diseases we serve.
137. At the state level the only person I have found that can always help me is Jackie—others seem inadequately trained in the area of genetics. If a child has a disorder we need to know about it regardless if child is seeing DMD or not!!
138. Education
139. N/A
140. N/A
141. N/A
142. N/A
143. Need more training on genetic disorders
144. I feel these babies need to see an MD who is a specialist in field and a Pediatrician for all check-ups and evaluations.
145. Limited resource materials in our facility to research defects or genetic disorders (ex.: textbooks, manuals, etc.)
146. N/A

147. Noncompliance with appointments
148. Transportation
149. Not enough time
150. Providing readily available services easily accessible for patients
151. N/A
152. N/A
153. Lack of knowledge about genetic disorders
154. N/A
155. Area of county located on Louisiana line. Services are long distance to MS state providers and poor transportation services; we are rural area with growing population
156. Long wait times before seeing specialist
157. N/A
158. Need another genetics doctor in the State
159. N/A
160. N/A
161. None
162. N/A
163. N/A
164. N/A
165. Inadequate knowledge and skills
166. N/A
167. As listed above, no specialist nearby for patients in this area
168. N/A
169. N/A
170. No close genetic counseling in area
171. N/A
172. Decreased education levels in pt. population—decreased comprehension of plan of care on pt's part.
173. Detailed counseling to parents regarding the severity of disease, complications, danger signals, long term outcome
174. N/A
175. Lack of patient education; lack of genetic counseling service
176. Lack of awareness among physicians and lay public
177. We are expected to provide many specialized services without reimbursements. Program directors make decisions that negatively affect our abilities to provide appropriate patient care.
178. Reimbursement for special services, formulas, etc. Reimbursement in post-21 year olds or others not on Medicaid and without insurance.
179. N/A
180. Difficulty finding funding for performing diagnosis tests—DNA studies.
181. Need centralized specialty clinic for caring for patients
182. Communication between providers
183. Simplify a case management problem—they need a point person who helps keep them on

- track for multiple provider therapies.
- 184. N/A
 - 185. N/A
 - 186. Having referral sources throughout the State; need good case management
 - 187. N/A
 - 188. N/A
 - 189. Social work services to identify and arrange transportation to all services available for child.
 - 190. N/A
 - 191. N/A
 - 192. N/A
 - 193. Treatment options; provider options
 - 194. N/A
 - 195. Biggest problem seems to be coordination of care and knowing who to refer to from primary doctor.
 - 196. Communication between service providers. Some families can't serve as care managers. Others do a great job.
 - 197. N/A
 - 198. N/A
 - 199. N/A
 - 200. N/A
 - 201. Family counseling
 - 202. N/A
 - 203. Communication between providers
 - 204. None
 - 205. N/A
 - 206. N/A
 - 207. N/A
 - 208. N/A

Survey on Genetic Services in Mississippi to Providers

5. What aspects of your program are especially helpful to patients and their families?

(N/A = No Response)

1. N/A
2. I do not work directly with genetics, but have some contact being one of a few and providing the knowledge.
3. N/A
4. N/A
5. N/A
6. Our facilities/employees; availability of resources
7. Developmental assessment and follow-up; physical therapy; occupational therapy
8. Cytogenetics lab has very good return of results.
9. N/A
10. Patient care we provide
11. Prenatal diagnosis and preparing for the birth of child with special needs.
12. Health dept. and social workers can help entire family and/or referral
13. N/A
14. Great pediatric care! Lay home visitor program with parenting classes
15. N/A
16. The loving, spiritual atmosphere with examples practiced, educational classes, and handouts for mother or father present with child.
17. N/A
18. N/A
19. 24 hour outpatient care
20. N/A
21. N/A
22. The OB/GYN department at UMC will accept and treat anybody regardless of race, insurance, etc.
23. N/A
24. Have genetic specialists available, good support system
25. N/A
26. On-going primary care with special focus
27. We provide transportation, follow-up appointments are readily available, good referral base.
28. Free access to physicians to ensure their questions and 24 hour call coverage
29. N/A
30. Provision of a medical home
31. Treating acute illness
32. N/A
33. N/A

34. N/A
35. N/A
36. N/A
37. N/A
38. 24-7 coverage by M.D.
39. Obtaining equipment (wheelchairs, etc.)
40. N/A
41. N/A
42. Quality care locally, communication with specialists good when initiated here, some ability to coordinate services.
43. N/A
44. N/A
45. N/A
46. N/A
47. N/A
48. N/A
49. N/A
50. N/A
51. Quality of care, usually same day appointments
52. Medical home to provide pediatric care
53. N/A
54. N/A
55. N/A
56. N/A
57. N/A
58. Early intervention, specialists at UMC
59. N/A
60. N/A
61. I personally go out of my way to ensure that their needs are met.
62. N/A
63. N/A
64. Medical home
65. Local care, availability of ped. specialties in Jackson
66. N/A
67. We are available and willing to care for them.
68. N/A
69. N/A
70. N/A
71. N/A
72. Try to educate whole families, making them aware of future consideration of child with above problems.
73. N/A
74. We are readily available for acute problems but do not function as overall coordinators of care for these patients.
75. Public health clinic, accepts Medicaid and Medicare

76. N/A
77. N/A
78. Medicaid, Transportation
79. Specialists at UMC
80. Nutrition, social work, OT, PT, Speech consultations
81. N/A
82. N/A
83. Blake Clinic
84. I am a general pediatrician, therefore I only identify children with potential problems and refer if needed.
85. Identify needs and assessing general health issues. Coordinating referrals.
86. N/A
87. N/A
88. N/A
89. Coordinating therapeutic services; resource information
90. Early intervention/helping families make their choices for services
91. N/A
92. Intervention (home-based)
93. N/A
94. Coordinating the services needed
95. My program helps parents understand the disorders that their child may have with the help of our library to provide tapes, hand-outs, toys, etc. to help parents understand their child.
96. Free dev. evaluation and services paid for by Medicaid/free to family---home based services are very helpful.
97. I think my program is the most helpful of any other program offered through the state but there's still room for lots of improvement.
98. The resources/services that are available. The support that is given to the families through the different service providers.
99. The family centeredness
100. Genetic social worker (or nurse) availability
101. N/A
102. Support, encouragement, and availability
103. Service coordination
104. Coordination of services--support (emotional) for the families
105. The program itself helps parents with the development of their children. Many parents need help setting up services, knowing who to call and where to go...we provide the parents with the needed info and assist them in arranging services and understanding the need.
106. Linking families to appropriate service providers
107. N/A
108. Multiple programs available--help in coordinating services
109. Local support for parents/families
110. N/A
111. N/A

- 112. N/A
- 113. N/A
- 114. N/A
- 115. N/A
- 116. We refer all at-risk children under age 3 to EIS and have a very active program.
- 117. Children's medical-genetics, early intervention
- 118. N/A
- 119. N/A
- 120. We are able to follow-up closely with pt's and families; provide home service; local CMP clinic monthly; access to UIC and nutritional and social services in-house.
- 121. N/A
- 122. N/A
- 123. N/A
- 124. N/A
- 125. We are up to date on needs-referral availability.
- 126. Teaching on genetics disorders
- 127. Less travel for them
- 128. EI
- 129. CPTS, Early intervention, PARM
- 130. N/A
- 131. We refer all children under age 3 to EIS.
- 132. N/A
- 133. Able to get several services at one time - CMP, WIC, IMM
- 134. N/A
- 135. Counseling people are less afraid of what they know; its what they do NOT understand or know that creates fear.
- 136. N/A
- 137. N/A
- 138. We provide the medication and needed equipment to the patients.
- 139. Educating family members as well as giving support and empathy.
- 140. N/A
- 141. N/A
- 142. N/A
- 143. Coordination of all services
- 144. PHRM Program/CMP application and renewals/Medicaid applications/WIC services/vaccines
- 145. Closeness to homes of pts. and family
- 146. N/A
- 147. First Steps and CMP
- 148. WIC and renewal application for CMP
- 149. Referrals to UMC and Dr. Bock
- 150. Puts patients in touch with specialist for care
- 151. N/A
- 152. N/A
- 153. Genetics Clinic

154. Counseling and close follow-up
155. Cost, information from state programs located at Health Dept. Explanation of programs made clearer.
156. We provide services such as transportation and sliding scale fee to patients in financial trouble.
157. Counseling
158. Counseling, information
159. Prompt referrals when necessary. Walk-in without prior appointments.
160. N/A
161. Availability of service
162. N/A
163. N/A
164. N/A
165. N/A
166. N/A
167. N/A
168. N/A
169. Availability of on-site counseling services
170. Good MD's
171. N/A
172. Indigent medications program
173. Support groups are very essential.
174. N/A
175. Laboratory service and follow-up; new technique for accurate diagnosis
176. As far as I know we're the only ones in the state who provide comprehensive services.
177. We provide very comprehensive services with 800 # access, satellite clinics, and extensive networking and coordination with local providers.
178. Comprehensive program
179. N/A
180. Manage seizures, motor handicaps, spasticity
181. Medical expertise in these conditions
182. Availability to me and then hopefully to subspecialists
183. I am well trained and used to chronic care issues and have UMC resources.
184. N/A
185. N/A
186. Multi-disciplinary approach, physician, psychology, nursing, social work
187. N/A
188. N/A
189. N/A
190. N/A
191. Management of neurologic problems
192. N/A
193. Clinical care; education
194. CF Center
195. 24 hour availability; prenatal diagnosis of future pregnancies

- 196. Medical care management; behavioral counseling
- 197. N/A
- 198. We're close to home for many people.
- 199. N/A
- 200. N/A
- 201. Comprehensive care
- 202. N/A
- 203. One-stop medical care
- 204. ER
- 205. N/A
- 206. N/A
- 207. N/A
- 208. We do treat these patients and not many will – dentistry!

SURVEY ON GENETIC SERVICES IN MISSISSIPPI TO ADMINISTRATORS

We want to improve access to genetic services in Mississippi. To make these improvements, we need to hear from you about your experiences as a program manager/administrator. Please answer these questions about services and write down any additional suggestions on services not covered.

1. Does your program serve patients who have birth defects, genetic disorders (for example: sickle cell, Down syndrome, spina bifida, galactesemia, cystic fibrosis, hemophilia, etc.)?

Circle one: Yes or No

2. The following issues may be important in managing care for patients with these diagnoses. Please rank the issues shown: enter 1 by the issue you perceive as most important in your program's work with these patients, 2 for the next most important, etc. If the statement does not apply to your program, please enter NA.

- ____ Don't have available enough skilled professionals to staff program.
- ____ Reimbursement rates insufficient for our services.
- ____ Transportation to our location is a problem for our patients.
- ____ Availability of financial coverage for our patients not clear.
- ____ Overall management of patients services is not coordinated among providers
- ____ Incomplete information available on patients referred to our program from other providers
- ____ Not having specialized doctors available for referral of our patients close to their homes.
- ____ My office staff or I are required to fill out too many forms.
- ____ Lack of affordable childcare for patient's children.
- ____ System of care is difficult to figure out: Not sure how to refer patient for follow up.
- ____ Limited availability of training programs to keep our staff skills up to date
- ____ Appointment keeping is a problem for our program.
- ____ Other providers not aware of nor do they understand our services
- ____ Long wait for referral appointments for our patients to other providers.
- ____ Long wait for follow-up appointments for our patients here
- ____ Do not have a list of support groups available for referral of parents.

3. Complexity of eligibility determination process makes it hard for our staff to help patients.

Circle one: Yes or No

4. What problems do you see as critical in managing your program for patients with genetic disorders?

-
5. What aspects of your program are especially helpful to patients and their families? _____

-
6. Please tell us the county in which your program is located _____

Thank you! Please return in the stamped addressed envelope provided by June 25.

Survey on Genetic Services in Mississippi to Administrators/Managers

4. What additional problems do you see as critical in managing your program for patients with genetic disorders and disabilities?

(N/A = No Response)

1. I hear a lot of complaining regarding traveling all the way to Jackson for a doctor's appointment—so a lot of rescheduling goes on.
2. N/A
3. N/A
4. N/A
5. Need more awareness, more staff
6. N/A
7. N/A
8. None
9. None
10. N/A
11. Referrals no longer received
12. N/A
13. Transportation for patients; lack of childcare for other siblings (M'CAIP Transportation does not transport siblings); lack of 800 # for patients
14. N/A
15. Need more genetic clinics and extended follow-up for patients
16. N/A
17. Our staff needs more training on services and available services
18. Getting the referral information in a timely manner
19. Educating physicians regarding the importance of early follow-up
20. N/A
21. Lack of coordination of services, lack of on-going financial resources, lack of proper medical follow-up in a timely manner, lack of collaboration by service provider and professional staff.
22. N/A
23. N/A
24. # of staff assigned to program
25. N/A
26. N/A
27. N/A
28. N/A
29. N/A
30. N/A
31. N/A
32. N/A
33. N/A

- 34. N/A
- 35. N/A
- 36. N/A
- 37. Referrals for non-medical resources needed
- 38. N/A
- 39. There is significant lack of understanding for the time and resource expenditures needed to manage some genetic conditions with limited resources.
- 40. N/A

Survey on Genetic Services in Mississippi to Administrators/Managers

5. What aspects of your program are especially helpful to patients and their families?

(N/A = No Response)

1. Information resource – I usually get them appointed or give them phone numbers to help themselves.
2. Regional clinics for speciality like orthopedics, genetics, etc.
3. Specialized doctor and clinic
4. We provide a local contact and help link patients to specialty clinics.
5. Sickle cell case management, local clinics
6. N/A
7. N/A
8. Referral sources
9. Referral sources
10. Case management – One key person as contact and direction to all necessary services.
11. N/A
12. We have a myleo clinic in which providers such as ortho, urologist, neuro, come to the clinic on same day to see patients.
13. Access to genetics social worker/CM
14. N/A
15. Developmental evaluations – services provided
16. N/A
17. Support and education and linkage
18. All services
19. We provide a personal touch to the services we deliver.
20. N/A
21. Some coordinated service delivery in many of our clinics, however more is needed.
22. Appointment with genetic clinic
23. N/A
24. Case management, financial assistance
25. N/A
26. N/A
27. N/A
28. N/A
29. N/A
30. Any program availability is helpful.
31. Children's Medical Services
32. N/A
33. N/A
34. Multi-programs and accessibility

- 35. Financial assistance through sliding fee scale and assistance with coordination of specialty care.
- 36. Quick access – No insurance or cash needed for entry to service.
- 37. Ability to provide services regardless of financial reimbursement
- 38. Accessibility
- 39. Centralization helps coordination; 800 # access; Care is individualized and comprehensive; Patients are involved in decision making.
- 40. Personal assistance with application process and accessing services after enrollment.
- 41.